“Here, there is Nobody”

An ethnography of older people's end-of-life care in hospital

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Abstract

Keywords: ethnography, suffering, compassion, embodiment, end-of-life care, palliative care, acute hospital, older people, dementia, ethical decision-making

The alleviation of suffering lies at the core of compassionate end-of-life care, yet little is known about the lived experience of suffering. Motivated by a series of reports on poor care of older people in hospital, this study addresses suffering in older people at the end of life in an acute hospital ward in the United Kingdom. Methods were developed from a synthesis of ethnographic fieldwork and phenomenological interpretation.

Data were collected using participant observation on an acute care ward for older people in a hospital in Northern England, over 186 hours between June and August 2015. Data included field notes, documents, photographs and informal interviewing. Staff and patient participants were identified using theoretical sampling. Data were analysed using a hermeneutic approach involving a continuous process of analysis, further data collection, posing of problems and questions, and interpretation. This cyclical approach to the data enabled the development of interpretive perspectives which could then be further explored in the field.

Findings suggested that care for older people was shaped by competing ideologies of care and organisational regulatory processes. Particularly when there was ambiguity regarding prognosis, there was a tendency for care to default to a ‘rescuing’ acute care model. Through exploring the experiences of individual patients and placing these in the context of cultures of care, I suggest that iatrogenic suffering was a significant concern that often went unrecognised. Patient-centred goals must be more focused upon avoidance of iatrogenic suffering. Recommendations include innovations in clinical education and multiprofessional working.

Figure 1: We are the guardians of what we witnessed [Behar 2014]

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Chapter 1: Introduction

My thesis is concerned with exploring the suffering of older people in hospital who are approaching the end of life. I present a study which investigated how suffering was experienced and expressed by older people in this setting, and critically examined the kinds of social, environmental and interpersonal factors that influenced its experience and expression. I investigated this on two levels. At the ward level, I examined how the broader cultural and social context impacted upon the processes and practices of caring for those who were suffering. On an interpersonal level I explored patient experience, through the use of sensory ethnography which enabled in-depth observation of suffering experiences in context.

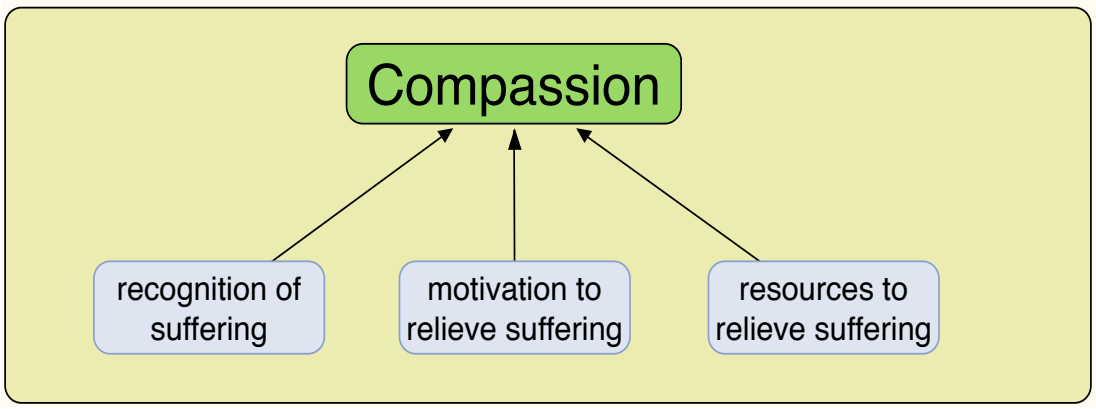
1.1 Background

Recent reports highlight concerns over poor hospital care, particularly for older people (Parliamentary and Health Service Ombudsman 2011, 2015; Francis 2013b; Neuberger *et al.* 2013). Improving the care of people dying in hospital was highlighted as a research priority in a recent public consultation (Palliative and End of Life Care Priority Setting Partnership, 2015). The government's response to the Francis Report (Department of Health 2014) identified that it was imperative that we understand the link between culture and compassionate care. This requires us to understand more about the nature of compassion in this setting.

The alleged 'compassion deficit', seen as contributing to suffering and poor care for older people in the health service, has motivated calls for increased education on compassion (Willis 2012), values-based recruitment (Francis 2013a) and regulation and monitoring of compassionate care (Parliamentary and Health Service Ombudsman 2011). These three recommendations appear to locate the blame for the apparent compassion deficit at the feet of the caregivers, particularly nurses.

The definition of compassion is contested (Van der Cingel 2009; 2011) but for the purposes of the current study it was understood to be a response to suffering, requiring the recognition of suffering in the first instance, the intention to alleviate that suffering, and the ability and resources to respond to that suffering with appropriate action (Chochinov 2002; Sinclair *et al.* 2016). This is illustrated in **Figure 2** below:

Figure 2: Compassion conceptualised (adapted from Gilbert 2005; Wilson et al. 2007; Van Der Cingel 2009)



Paley (2014) argues that rather than a *"failure in compassion",* the findings of the Francis Report suggested a *"failure to* ***see suffering****"* emphasising that the improvement of individual virtues such as compassion fails to consider the *"interlocking set of contextual factors that are known to affect social cognition"* (p1). Suffering is a complex human experience, with no agreed definition (Cassell 1998; Wilkinson 2005; Kellehear 2009; Best *et al.* 2015). Despite this lack of conceptual clarity the word suffering is at the core of the World Health Organisation's definition of palliative care (WHO 2010), and is prominent in palliative care policy, guidance and literature (for example Department of Health 2008; National Cancer Peer Review 2012). Furthermore, suffering is cited in the literature on assisted dying as the core concern when living with life-limiting illness (Hendry *et al.* 2013).

In this thesis, I explored the suffering of older people approaching the end of life in inpatient hospital wards. My findings suggested that suffering experiences were highly variable and demonstrate that there was much to be learned from hearing the stories and from witnessing the experiences of those who were suffering. It was through this direct contact with such experiences that we may

be able to interrogate the issue of poor care and understand it in relation to some of the experiences of older people in this environment. Through understanding suffering, we might make progress towards enhancing compassionate care.

Aims

My aim was to investigate how suffering was experienced and expressed and to critically examine the kinds of social, environmental and interpersonal factors that influenced suffering.

Objectives

In order to achieve these aims I set out to:

1. Explore the context of care in a hospital ward where many patients were older people at the end of life
2. Observe patients in the last months of life and illustrate a range of themes representing their suffering experiences
3. Draw inferences relating to the interface between context and experience
4. Consider potential applications of findings to enhancement of compassionate care

1.2 Rationale

First it is necessary to discuss the rationale for choosing to focus on this particular demographic group in this particular context. To this end, I consider why this research looked at hospital care, why it focused on older people, why it narrowed this to those thought to be at the end of life, and why it included participants with cognitive or communicative impairment.

1.2.1 Why Hospital?

The Reports described above focused on hospitalised patients. It is perhaps in this setting that people are most at risk of poor care, and most distanced from their usual resources and sources of support. I also elected to base this research in a hospital because this remains the most common place of death (NEoLCIN 2011; Murtagh *et al.* 2012). A significant amount of hospital care particularly for older people can be framed as end of life care, if adopting the view that this refers to the last year of life as defined in the End of Life Care Strategy (Department of Health 2008a).

Even for those who do not actually die in hospital, a significant proportion of the last year of life is likely to be spent in hospital on account of the complications of life-limiting disease (Aminoff and Adunsky 2006; Georghiou *et al.* 2012). Most people are admitted to hospital with the intention (from both the patient and the professional) to investigate, diagnose or treat a particular condition, even when this may be long term and not possible to cure. When in hospital acute needs are often prioritised over more subtle aspects of human suffering (Gardiner *et al.* 2013).

There is variation in organisational culture, regional priorities, demographics and technical facilities within and between hospitals. Yet as Van der Geest and Finkler observe, hospitals also *"reflect and reinforce dominant cultural and social processes"* (2004, p1995), rendering them important locations in which to explore how these processes are played out in the everyday activities taking place therein.

Hospital wards specialising in older people's medicine typically care for patients with a variety of conditions, with differing levels of cognitive impairment, and at different points in their illness trajectory from curative to palliative. This clinical setting therefore provides a potentially rich source of insight into the lived experiences of people who are currently under-represented in the end of life care literature, and whose suffering may be less likely to be attended to by staff (Bridges *et al* 2010).

1.2.2 Why Older People?

Older people in hospital are a primary focus of current concerns about compassionate care (Addicott and Ashton 2010; Brereton *et al.* 2012; Cornwell 2012). They are particularly vulnerable to social, spiritual, physical and psychological aspects of suffering, informed by a range of factors (Alexopoulos 2005; Brocklehurst and Laurenson 2008). Many experience the effects of multiple clinical conditions and cognitive impairment (Dixon *et al.* 2015). Further, their experiences are shaped by broader social and cultural issues such as ageism and, consequently, marginalisation within the healthcare setting (Bytheway 1995; Bodner 2009; Thomas and Milligan 2015).

In the UK, the majority of people over 65 die in hospital (NEoLCIN 2010, 2011). Even for those who die elsewhere (for example, at home, in a hospice, or in a care home) the last year of life is often associated with at least one hospital admission (Clark *et al.* 2014) particularly for people with chronic organ failure such as chronic obstructive pulmonary disease (Gadoud and Johnson 2011; Murtagh *et al.* 2012). Often, older people are unable to remain at home at the end of life because of a lack of available care, whether from widowhood or illness of co-resident or spouse, family members who live away or who are out at work, or unavailable or inappropriate social care provision. Older people frequently live alone, possibly because of widowhood. Therefore, many older people in hospital are there for social care or rehabilitative rather than curative, reasons even if at the point of admission there are expectations and hopes for something more. In many cases, there is no possibility for active treatment to reverse their clinical conditions, hospitals are largely structured around a biomedical model of illness and it is known that there are problems in providing the social aspects of care in this setting (Brown and Walter 2014).

1.2.3 Why People with Communication Barriers?

The experiences described in this thesis included the stories of some patients who were unable to communicate meaningfully using words. This was an intentional aspect of the study. Many older people in hospital towards the end-of-life are likely to experience cognitive impairment, whether through existing conditions such as the dementias, or through temporary acute states such as

infection-related delirium (Hughes *et al.* 2005) or the effects of depression, which is an under-recognised problem in older people that can profoundly affect people's ability to communicate (Alexopoulos 2005). People with dementia or cognitive impairment formed the majority of the subjects of investigations in the Francis Report, and yet are significantly under-represented in research. It might be argued that this is largely because of pragmatic and ethical challenges in recruitment and conduct of relevant and appropriate research. This mismatch means that the suffering experiences that are well documented in the literature may only have limited relevance to the experiences of those who appear to be most at risk of suffering in the last months of their lives. This thesis hopes to address this inequality in representation.

The issue of marginalisation is also a concern in acute care settings. People unable to communicate are less likely to be able to make their care needs known and are less likely to complain about their care. Some may experience being avoided by the healthcare team because the condition of their bodies and minds engenders a reaction of disgust (Holmes, Perron and O'Byrne 2006; Picco *et al* 2010; Simpson 2012; Consedine *et al* 2013). It might be argued that this may result in distance rather than connection. Furthermore, there are concerns that paternalistic attitudes that pervade healthcare systems may lead to the needs of older people being assumed, rather than based on authentic connection and assessment (Cornwell 2012).

1.2.4 Why End of Life?

People in hospital may encounter specific problems in their last year of life. There is often ambiguity about prognosis or the terminal nature of certain chronic disease, as well as uncertainty and ambiguity about other aspects of the future, including place of care or spiritual needs (Gott *et al.* 2004; Seymour 2007; Boston *et al* 2011; Lee, Froggatt and Simpson 2013). It is a time of life when physical illnesses often give rise to difficult symptoms such as pain or fatigue, which can be associated with suffering (Cherny *et al.* 2015).

There is some discrepancy between definitions of palliative and end-of-life care (see for example Connor 2008; Pastrana *et al.* 2008; Hui *et al.* 2014). Palliative care seeks to improve *"the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual"* (WHO 2010). This definition has been challenged on philosophical grounds by Randall and Downie (2006) and will be further discussed in chapter 5. In the meantime, I use the term 'end of life' as defined in the End of Life Care Strategy (DoH 2008) to describe the patient participants in this study. This definition refers to care provided in the last year of life although this is not a fixed prognosis, but more of an approximation in order to delineate the boundaries of care. People may live longer than this with progressive terminal diseases, or they may die sooner. Although work is underway to develop prognostic indicators (O'Callaghan *et al.* 2014) this area is not well understood. In order to identify those participants who might be in the last year of life, I adopted the 'surprise question' as a catalyst for conversation with the clinical team (Connor 2008). This involves asking care providers whether they would be surprised if an individual were to die in the next twelve months. In the notoriously inaccurate field of prognostication, it is thought that this question – given that it relies on clinical intuition – is as good as any of the existing, unsubstantiated, prognostic indicator tools (Downar *et al.* 2017)[1].

A significant proportion of hospital inpatients are thought to be in the last year of life, and the majority of these are over seventy. A prevalence cohort study by Clark *et al.* (2014) identified that of a group of over 10,000 hospital patients, around 29% had died within a year of admission to hospital. Unsurprisingly, mortality rose sharply with age. Those over 85 were three times as likely to have died with the year following discharge as younger patients. Furthermore, patients admitted to medical specialities were more likely to have died than those admitted for surgery, perhaps reflecting again a demographic whereby those patients eligible for surgery are overall a younger and fitter group,

[1] I consider this issue further in chapter 5 when discussing different approaches to care of the dying

whereas older people are more likely to be at the advanced stages of long-term progressive illnesses. This study was substantiated by current data supporting hospital as the most common place of death for older people in the UK (NEoLCIN 2010, 2011). In the region of the UK where this study was conducted, 89.9% of people who died in hospital in 2013 had been admitted through A&E. In the NHS Trust area in which this research took place there were 1794 deaths in the last quarter of 2015, of which 717 (42%) took place in that person's 'usual' place of residence (ONS 2015) implying that 58% were in another place, likely to have been an acute hospital.

The last year of life is often characterised by uncertainty as the criteria for success of treatment becomes less clear and the risk of iatrogenic harm increases. The trajectory of illness may feature multiple fluctuations, some (such as in COPD) by severe exacerbations that may lead to people being very close to death, followed by full or partial recovery. This lack of predictability in the last year of life can be a source of distress both for patients, those important to them, and their health and social care professionals. It can also represent a time of transition in terms of social roles and spiritual awareness (Best *et al* 2015) and is known to be a time of vulnerability to psychological difficulties (Abraham *et al* 2006).

1.2.5 Section Summary: Why is This Research Needed?

This study addressed the nature of suffering of older people experiencing end of life care in hospital; an area which has been largely excluded from current research. The essence of enabling a 'good death' is for health and social care professionals to respond effectively to suffering and to seek its alleviation or minimization (George 2009; Cassell and Rich 2010). There is an increasing body of literature that suggests that the suffering of older people is frequently ignored (Aminoff and Adunsky 2004; Lesho *et al.* 2009; Krikorian *et al* 2012). The experiences of those who Chapple refers to as the 'disenfranchised dying' (2010) are under-represented in current research (Sleeman and Murtagh 2014). Frequently, people are excluded from research because they are considered too vulnerable, ill or unable to participate. This may partially reflect methodological challenges, and partially a widely shared perception that dying

people should not be burdened by being involved in research (Rhodes and Small 2014). This paternalistic approach has recently been challenged, recognising that even those with significant burden of illness and disability may wish to participate in research to improve care (Gysels, Evans and Higginson 2012).

Numerous studies have attended to the nature of end of life care in hospital, but there is very little research that examines the experiences of dying people themselves in the last months of life. Those studies that do consider suffering primarily involved patients diagnosed with illnesses such as cancer, in which participants had capacity to be interviewed in relation to their experiences, and furthermore, in which the last year of life was relatively straightforward to identify. Identification of people dying from diseases other than cancer is more problematic and presents numerous clinical challenges (Department of Health 2008a) so it is reasonable to presume this renders this population similarly hard to identify for the purposes of research, which may partly account for the lack of studies.

1.3 Structure of the thesis

Section 1: Development of the Study

Section 1 outlines how the study developed, including the establishment and clarification of the philosophical perspectives and how this informed development of the methodology.

In chapter 2 **("The Finger Pointing at the Moon")** I argue that, despite methodological and practical challenges, suffering is a valid object of enquiry within a social constructionist research paradigm. I outline my epistemological and ontological position in relation to the development of a methodology. I appraise the potential contributions of anthropology and phenomenology to the study of suffering *in situ.* I consider issues such as intersubjectivity and embodied awareness, drawing upon Merleau Ponty's (1962) phenomenology of perception. I then appraise the ethnographic work of Geertz (1973) and

consider the contribution of thick description to understanding of ambiguous phenomena.

Chapter 3 **("Embodied Ethnography: A Synthesis")** focuses on reviewing studies of end of life care that address aspects of this topic, providing a critical overview of their methods as well as summarising their findings. I use this review to justify the way in which I take my methodology forward. Next, I describe the synthesis of ethnographic and phenomenological perspectives which I decided to use as my methodology. The synthesis is framed as an embodied ethnography in which the observation is framed through all of the senses and is positioned as a device through which to achieve intersubjective awareness of the embodied suffering of another. I describe the elements I intended to include in my ethnography: verbatim accounts of informal conversations, thick description of body language, embodied experiences, the sensory landscape of the field, and reflexivity.

Section 2: The Ethnography

Section 2 incorporates chapters 4 -7 and consists of the ethnographic account, derived from field notes and analysis of documents and photographs. Across these chapters I address in turn the environment and culture of care, the experiences of participants with whom I spoke, and finally the experiences of participants unable to communicate their experiences verbally.

In chapter 4 **("In the Field")** I describe my observational research method, addressing ethical considerations, engagement in the field and my approach to fieldwork and data collection. I describe the ward and the broader institutional and political context of the study. This is followed by thick descriptions of aspects of the ward, including its physical environment and the routines of care that typify practice. The intention is to enable the reader to place the subsequent ethnography in context, to be able to imagine through the use of thick description the everyday experiences of life on the ward.

In chapter 5 (**Rock, Paper, Scissors)** the field is described in terms of the clinical team and the routines and rituals that shape and inform everyday clinical practice. In this chapter I describe how the clinical area was characterised by

three ideologies which I term *rescue*, *rehabilitation* and *release*. These sometimes align, but at other times they compete or conflict, and this impacts on care. Theoretical perspectives of Bourdieu (1990; Bourdieu and Wacquant 1992) are drawn upon to analyse mechanisms of social and cultural capital within the health and social care team, and the dominant scripts that characterise everyday practices on the ward.

Chapter 6 **("Here There is Nobody")** introduces the first group of five participants. They were patients on the ward during the time of the study. I focus on my accounts of their experiences, as I observed them. Each account attends to a different aspect of suffering, and although each narrative stands alone, there were common themes which I have drawn together in the conclusion of chapter 6. This chapter incorporated a significant proportion of reflexivity in order to attend to the embodied and intersubjective elements of suffering. Although informed by the phenomenological positions outlined in earlier chapters, this chapter only minimally draws upon theory. Its aim is to present the patient narratives and themes for subsequent discussion in chapter 8.

Chapter 7 **("White Knuckles, Tapping Spoons")** introduces a new group of six participants – those who were unable to verbally articulate their experiences. The shared characteristic of these participants is that they had all been deemed to be lacking in mental capacity for the purposes of participating in the study, as well as for many of the day-to-day decisions that needed to be made on their behalf. For these participants, the ethnography was presented in a different way, and greater attention was paid to the embodied expression of suffering. As with chapter 6, there is minimal use of theory and the chapter aims to present a set of patient narratives, each illustrative of different facets of suffering.

Section 3: Analysis, Discussion and Conclusion

The final section, chapters 8-10, explores the concept of suffering through a pragmatic review of philosophical, literary and clinical perspectives.

Chapter 8 **(The Nature of Suffering)** considers how the findings in Chapters 6 and 7 add to existing understanding of the concept of suffering. This takes the

form of a pragmatic literature review, addressing ideas of suffering from philosophical, clinical and sociological perspectives, complemented by the findings from the previous two chapters. I attest to the nuanced nature of suffering illustrated by the participants' narratives and consider the resonance of these stories with what is known about the suffering experience.

Chapter 9 **(Iatrogenic Suffering)** examines the context of the narratives in more depth, drawing upon Illich's (1975) notion of iatrogenic harm. I consider how a healthcare culture that was defined by risk aversion, efficiency and regulation may have contributed to poorer experiences of end of life care in older people. In particular, I suggest that in this study, the ward culture contributed to particular forms of suffering that go unrecognised, because the suffering originated from within the very culture that was attempting to alleviate it. I argue that this in part had to do with the comparative power of the ideological scripts relating to rescue and rehabilitation within the overall position of the health service. Furthermore, the multiple levels of context at play meant that even where nurses were in a position to alleviate suffering, the weight of the broader sociocultural influences were such that they were unable to do so. Therefore, to attempt to shoehorn compassion into care provision at this level failed to recognise the influence of these larger powerful processes.

Finally, chapter 10 **(Engaging with Suffering)** considers the potential of this study to inform education and clinical practice. I make two suggestions that arose out of my reflections during the course of this research. Firstly, I reflect on my experiences of observing care as a novice researcher, and in particular on the depth of insight that becoming an 'observer' afforded me in relation to patient experience and healthcare practices. My conclusions from this experience led me to suggest a potential innovative application of anthropological research methods in pre-registration nursing education. I will consider the potential utility of observational methods in early clinical placements during pre-registration nursing training as a means of enhancing insight into suffering experiences, potentially enhancing internal rather than external motivations for compassionate care. Secondly, a model for guiding multidisciplinary team decision-making in older person's care is considered,

based upon the premise that suffering results from misalignment of goals of care within the ideologies discussed in chapter 5.

1.4 Summary

In this thesis, I addressed three key research questions:

1. *How was suffering expressed and experienced by older people at the end of life in hospital?*
2. *How do social, environmental and interactional factors appear to impact upon experiences of suffering?*
3. *What can we learn from this that might inform how we care for older people at the end of life?*

These questions were addressed through the use of observational research methods, grounded in a constructionist paradigm that locates suffering within the social context in which it was experienced. I adapted existing techniques and developed a sensory ethnography that enabled the study of embodied suffering experiences. Across three findings chapters, I address in turn the environment and culture of care, the experiences of participants with whom I spoke, and finally the experiences of participants unable to verbally communicate their experiences. The ethnographic field notes were rendered into themed narratives. In my analysis, I considered how Illich's notion of iatrogenic suffering offers insight into the apparent invisibility of many of the forms of suffering that I witnessed, suggesting that much of this suffering was created by the environment and delivery of care as well as the social context of dying in the UK. In the final chapter, I make recommendations for clinical practice and education that relate to my findings.

There is a real need to understand the experience and contexts of suffering for older people, as well as the ways in which the healthcare environment contributed to this – either positively or negatively. There are no studies that specifically examine suffering in people in the last year of life in the hospital setting. Yet suffering is at the core of the philosophy of palliative care, and it is broadly recognised that quality of life and patient-centred care require greater

understanding of suffering. If more is known about situated influences on suffering then this might inform ways to enhance compassionate care.

Section 1: Development of the Study

Chapter 2: The Finger Pointing at the Moon

> *"Always remember, truth cannot be said, it can be shown. It is a finger pointing to the moon. All words are just fingers pointing to the moon, but don't accept the fingers as the moon" (Hsuan Hua / Buddha 1999)*

2.1 Introduction

In this chapter I outline four foundational premises, and examine each in turn to build a methodological argument that informs how the study was designed. I consider various epistemological and ontological challenges in researching suffering and suggest that despite these challenges, suffering is a valid object of inquiry within a social constructionist research paradigm. I appraise the potential contributions of anthropology and phenomenology to the study of suffering in situ, concluding with a description of 'embodied ethnography' which combines elements of these approaches.

The opening quote, originally attributed to Buddha in the Sūraṅgamasamādhi Sūtra, forms the premise for the present chapter. I aim to explore the nature and context of suffering in older people in an acute hospital ward. Suffering is subjective and idiosyncratic, complex in its manifestations, socially constructed, and contextual. The epistemological challenge confronting this research is to ascertain whether it is possible to research other people's experiences of suffering as it manifests in individual and relational behaviour. Inner experiences are intrinsically unobservable events, although as this chapter will argue it is possible to derive an approach to the study that enables the study of proxies to these inner worlds. This chapter outlines a methodological approach that is sensitive to these challenges, that recognises the complexity of suffering but nonetheless presents a case that it is a plausible object for research. To address these, I have been informed by theoretical perspectives drawing on anthropology and phenomenology. I defend subjectivity within the overall methodology, arguing that it is not possible to research a phenomenon as complex as suffering through objective means.

Cassell (1999;1991) observes that one cannot know as an outsider what the source of a person's suffering is, since it is intimately related to that individuals' personhood and values. To research suffering implies that suffering is an 'it' that can be observed. Suffering is not a tangible object as such, so it is necessary to discuss the extent to which it can nevertheless be an object of research.

Bourdieu advises that to gain understanding of complex social phenomena, we must *"learn how to translate highly abstract problems into thoroughly practical scientific operations"* (Bourdieu and Wacquant, 1992, p221). An important part of this is understanding the relationship between agent and action, subject and object, and self and other.

2.2 Methodological foundations

The methodology assumes the following four premises:

1. **Suffering is socially and culturally constructed and interpreted**
2. **Suffering is contextual**
3. **Suffering is expressed verbally and non-verbally**
4. **Recognising suffering relies on intersubjective processes that may not be objectively observed**

I now consider each of these in turn and outline how these have informed my methodology.

2.2.1. Suffering is socially and culturally constructed and interpreted

Suffering is socially constructed (Cassell, 1998; Frank, 2001; Kellehear, 2009; Kleinman, 1988). This means that the experience, expression and recognition of suffering varies between people, places and situations. It is impossible for two people to share an identical experience of a particular situation because each person brings their own unique history and stock of experiences, alongside their socially conditioned beliefs, to each situation. This thesis therefore draws on a constructionist epistemology, rejecting positivist ideas that phenomena can be

explained using the tenets of natural science. From a positivist perspective, evidence consists of objective data (Hammersley and Atkinson 2007). Positivism rejects metaphysical ideas that speculate about non-observable aspects of reality and suggests that in all areas of science from the 'natural sciences' of physics and mathematics to the social sciences, it is possible to proceed from observations to general laws. Further, positivism rejects introspection as being likely to distort perceptions. I argue that introspection (in the form of reflexivity) is not just inevitable but forms an essential component of the study of suffering, for empathy is essential in trying to gain perspective on another person's internal reality.

Social constructionism comprises the following features: (1) realist ontology is challenged (2) socially situated interactions create multiple realities (3) social interactions serve particular purposes and initiate actions, and (4) understanding human relationships involves examining the relationship between participants as well as between researcher and participants (Priya 2012). As such, no single view of suffering held greater validity over any other, and people's actions in relation to suffering could be understood as intentional. Within this paradigm, there is a focus on *"interpretation, multiplicity, context, depth, and local knowledge"* (Ramey and Grubb 2009, p80). Language and 'reality' are linked but are not claimed to be equivalent. It is more the case that language reflects aspects of reality.

Subjectivity and objectivity

Suffering does not manifest in objectively measurable ways. According to Schulz *et al* (2010, p775) there is a clear need to attend to the *"scientific study of the experience, expression, and interpersonal effects of suffering".* He claims that the reason that this is absent from the scientific literature is that we *"lack good measures of suffering humans"*. This need is echoed by Krikorian and Román (2014) who claim that *"although relief from suffering is essential in healthcare and palliative care, few efforts have aimed at defining, operationalising, and developing standards for its detection, assessment, and relief"* (p1). The implication is that if we had valid and reliable measures this could inform appropriate interventions to alleviate suffering. There have been

extensive efforts within the medical and nursing literature to develop assessment tools to screen for, or quantify suffering (see Buchi *et al.* 2002; Aminoff and Adunsky 2004; Beng *et al.* 2017, plus Krikorian *et al* (2013) and Best (2014) for a review). However, this endeavour has been beset by challenges such as the lack of a robust theoretical background to suffering (Krikorian and Román 2014).

All research, regardless of methodology or method, is underpinned by certain pragmatic assumptions (Paley 2011). The study of human behaviour and emotions presents a number of epistemological challenges, not least of which is the disjuncture between subjectivity and objectivity. Whether a researcher is observing a health professional or a patient, the object of research is the 'other'. Reporting another person's experience cannot be objective, as this would presume that what people say is a precise reflection of what they experience and is presented to the researcher in an unfiltered way. However it is known that recalling experiences, particularly difficult ones, involves multiple levels of interpretation, selectivity, reconstruction, error and motivations (Scarry 1985). There is no such thing as a transparent window into the inner life of another being. All is interpretation (Denzin and Lincoln 2011, p24).

This should not pose a problem in research as long as the researcher engages in a process of hermeneutic dialogue between self and field (Gadamer *et al.* 2004). It is perhaps through looking directly at our assumptions and prejudices that we may locate ourselves and gain insight into the choices we make and the actions we take. The only 'truth' that exists is that which relates to a person's direct experience of their own reality. As soon as this experience is interpreted by an observer, it becomes a new truth - that belonging to the observer (which may or may not resonate in part with the experienced reality of the sufferer). What is important is that the nature of subjective truth is acknowledged, as the presence of multiple voices in relation to a single person's experience of suffering is welcomed. There can be no single or empirical truth in relation to the experience of another person. There will always be perceptual filtering. The experience of suffering can only ever be interpreted, and these interpretations are themselves socially constructed and contingent. The suffering experience is

subjective; its interpretation by observers is subjective. And yet, it is also somehow related to objective structures that can be observed within the field.

This notion intersects with Bourdieu's theory of habitus which will be increasingly drawn upon as the thesis develops. Bourdieu emphasises the relationship between objective and cognitive structures through his concept of habitus (Bourdieu 1977; 1990). In his theory, humans are neither blind automatons that fulfil predetermined structural behaviours based on knowable rules; nor are they utterly guided by internal individualistic worlds. This epistemological stance challenges ideas of causality by suggesting that there is no rigid divide between agent and action. Devereux (1967) considers that it is important to analyse the nature of the junction between subjectivity and objectivity. Mutual understanding of communication between people will only ever be partial, and one ought to try and avoid trying to account for this by constructing theoretical explanatory structures. The potential tyranny of meta-narratives and over-theorising is further articulated by Davis (1999) who argues that ethnography requires a realist position in order to be able to draw appropriate boundaries between observations, beliefs and interpretation.

Clifford Geertz (1973) refers to the value of 'thick description' for conveying understanding of complex social phenomena to the reader. He describes an account of a gesture - a wink, communicated from one boy to another - in which the synthesis of *"a speck of behaviour"* and a *"fleck of culture"* constructs a gesture imbued with meaning that can be imparted from one person to another, as eloquently articulated in the following example:

> *"The object of ethnography: a stratified hierarchy of meaningful structures in terms of which twitches, winks, fake-winks, parodies, rehearsals of parodies are produced, perceived and interpreted, and without which they would not (not even the zero-form twitches, which, as a cultural category are as much non winks as winks are non-twitches) in fact exist, no matter what anyone did or didn't do with his eyelid" (Geertz 1973, p312)*

This description represents an important transition from objectivity to subjectivity, a move from the idea of observer as camera. The crucial difference is between accurately capturing the reality of a situation, and adopting a nuanced, interpretive approach to observation. Geertz describes that certain symbols (such as language, actions or practices) require interpretation in order to identify implicit assumptions about their function. For Geertz, all actions relate to people's understandings of the meaning of their actions. Diversity is part of the human condition and this is reflected in the multiplicity of interpretations he makes available in his account of *"winks upon winks".* He suggests that participants, as well as researchers, are engaged in ongoing interpretation of the ways they engage and act in the world. Thus, Geertz's ethnography is essentially a matter of *interpretation of interpretation*[2].

Causality

A key question in the study of social interactions is the extent to which observable phenomena can be said to be causally linked. Social constructionism is opposed to the notion that behaviour is deterministic, or that knowledge exists in some abstract form simply 'awaiting' discovery. Knowledge is understood as being created through a process wherein agents interact with one another and with their environments in ways that are purposeful (even if this purpose cannot be explicitly known) (Priya 2012). This links with ideas of causality. The notion of causality has largely been abandoned in sociological research, yet it continues to dominate much healthcare research. Within the positivist paradigm that dominates health research, this is generally presumed to be plausible; for example, one might postulate a link between consumption of saturated fats and the incidence of cardiovascular disease, or a causal connection between childhood neglect and attachment problems in later life.

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[2] *This is at odds with the kinds of universalizing practices described by other ethnographers such as Malinowski (eg Malinowski and Young 1979). Epistemological positions on ethnographic research still retain something of a schism. Scientific (or neopositivist) ethnographies (such as conversational analysis) challenge postcolonial, or narrative ethnography.*

In the process of interpreting suffering it is possible to develop ideas about causal links between events and suffering. Taken a step further, it would be possible to develop ideas about general rules that could be applied. But this approach raises two concerns. Firstly, it risks reduction of a person's suffering to the extent that their individual experiences are negated and simplified. Secondly, to search for general predictive rules can mean that unusual, subtle or less tangible examples of suffering are omitted in the drive for theoretical congruence and the development of some kind of theory of predicting suffering. Any causal links suggested by this study are both situational and tentative. Although one might observe an event followed by a response or reaction to that event, it is not possible to state with confidence that any meaningful process can be understood as a result of having observed that relational situation.

Suffering is invariably *about* something; it connects a person's present experiences with their emotional biography. Yet as an outsider, one can no more propose the existence of clear-cut causal links than offer a panacea for the suffering experience. So, it may be possible through careful study to offer some explanatory perspective as to a person's experience, but this serves the purpose of deepening insight into that experience at a particular place and time, and – crucially – through the lens of my own research skills. Another researcher studying the phenomenon may derive different explanatory processes to seek to understand what they have observed.

2.2.2. Suffering is contextual

> *"Believing, with Max Weber, that man is an animal suspended in webs of significance he himself has spun, I take culture to be those webs, and the analysis of it to be therefore not an experimental science in search of a law but an interpretive one in search of meaning. It is explication I am after, construing social expressions on their surface enigmatical." (Geertz 1973, p311)*

Suffering is best understood in the particular context of the cultural situation in which it is experienced. The 'culture' under scrutiny in this study is that of the

ward; staff, patients and visitors all play a part. Hospital cultures comprise multiple sub-cultures which continuously interact and overlap with one another (Fox 1979). The 'macro' culture of the hospital and the various broader influences on its practices seep into the 'meso' culture of the ward and the 'micro' cultures of different groups of people and professionals. In turn, these micro cultures exert their influence on the shape of practices at the broader levels. Patients, too, exert influence over practices, by virtue of the particular roles that they adopt, the illness and clinical dilemmas they present, and aspects of the relationships they develop with staff during their hospital stay.

Research undertaken in the 'real world' requires a flexible approach to methodology, drawing on a range of influences to ensure that the research question is attended to sensitively. Gray refers to the 'real world' as any setting in which *"human beings come together for communication, relationships, or discourse"* (2013, p4). Naturalistic studies are most closely associated with using observation as the primary method of data collection, and lend themselves well to the study of social systems. Social systems constitute:

> *"manifold, interlaced interrelations of meaning, to the indistinguishable, diffuse layers of meaning and the implicit horizon of the taken-for-granted, to the limits of what we are able to remember and the approximate character of understanding the other, and finally to the "paradox of rationality" on the level of everyday actions" (Eberle 2010, p136)*

Situated knowledge

The discipline of anthropology - the study of cultures - is the birthplace of ethnography. The method has been used to study cultures in situ for many decades. It has been defined as:

> *"an iterative-inductive research (that evolves in design through the study), drawing on a family of methods, involving direct and sustained contact with human agents, within the context of their*

> *daily lives (and cultures), watching what happens, listening to what is said, asking questions, and producing a richly written account that respects the irreducibility of human experience, that acknowledges the role of theory as well as the researcher's own role and that views humans as part object/part subject" (O'Reilly 2005, p3)*

In recent years ethnography has become increasingly recognised as having potential utility in the study of familiar cultures such as workplaces. There is a growing body of literature where ethnography has been used to answer questions relating to medical professional education (Becker *et al.* 1961), nursing practices in care of the dying (Costello 2001) and the culture of hospital as a place of care for the dying (Porock *et al.* 2009; Chapple 2010; Chan *et al.* 2017).

Ethnographic 'data' is predominantly unstructured at the point of collection. Fieldwork involves extended periods of time in the setting in which the phenomenon of interest takes place. During this time, the researcher undertakes detailed observations of people - their behaviour, actions, constructions - and a picture is gradually developed through listening, speaking, inquiring (Ingold 2014). Through immersion in a culture or situation, the researcher produces a written, detailed account of the kinds of practices that take place, and interpret, to varying degrees, the significance and meaning of these activities.

Despite the heterogeneity of the approach contemporary ethnographers generally agree that they produce situated understandings, not absolute knowledge (Hammersley and Atkinson 2007). They share the method of observation as the primary mode of data collection (although here, too, there are contested ideas of what comprises 'observation' - see Nader 2011). The validity of the ethnography is determined by the understanding created in both writing and reading it. It offers no more than less than *"glimpses and slices"* (Denzin 1997) of a situation. The utility of ethnography in understanding cultures is a product of that fact that *"insider and outsider views combine to*

provide deeper insights than would be possible by the "native" alone. This two-sided view produces a third dimension that rounds off the ethnographic picture, which is a theoretical explanation of the phenomena under study" (Goulding 2005, p300).

Bourdieu's *Theory of Practice* will be discussed in greater detail in the following chapters but is introduced now for the purpose of establishing the relationship between embodied aspects of the methodology and the situatedness of suffering within a sociocultural context (1972; Bourdieu and Wacquant 1992). Bourdieu refers to *'body hexis'* to describe socially-defined ways in which individuals occupy, position and use their bodies within the experiential world (Throop and Murphy 2002b). Bodily expression is an outward manifestation of *habitus*, a central concept referring to *"internalised set of structures (derived from pre-existing external structures) that determine how an individual acts in and reacts to the world"* (ibid, p186). Hexis is the performative aspects of habitus. Through adopting this theoretical lens, observation of nonverbal behaviour and signs may offer insight into suffering (in the case of patients) and into cultures of care (in the case of ward staff).

2.2.3. Suffering is expressed verbally and non-verbally

Because suffering is expressed in idiosyncratic ways, the methodology must be sensitive to intersubjectivity and interpersonal interaction. Over-reliance on words can mean de-emphasising of aspects of experience that are impossible to articulate. This has led to a call for embodiment as a valuable paradigm for ethnographic research (Csordas 1994). I now consider the contribution of Merleau Ponty's phenomenology of perception and suggest that by taking a phenomenological approach to ethnography, Csordas' concerns regarding inchoate aspects of experience can be addressed.

Embodiment and Phenomenology

Phenomenology is a school of philosophical thought rather than a defined approach to research. It originated in the work of Husserl (Duranti 2010) and is generally considered to be an approach to the problem of being, rather than a means of acquiring knowledge. It is concerned with describing the world rather than offering explanations for things. Phenomenology seeks a return to the essences of these phenomena (Husserl, transl. Moran 2001). The significance of the phenomenological position for the current study is twofold. In the first instance, it enables an approach to understanding suffering as an embodied and temporal experience in which people's actions can be understood as enactments of intentionality. Second, phenomenology offers insights into how conscious experience might be researched. Phenomenology's contribution forms part of the theoretical foundations of the phenomenon of suffering, but also the means of engaging with the phenomenon as a subject of research. Primarily, I have drawn upon ideas from Maurice Merleau Ponty's *'Phenomenology of Perception'* (1945 / 2013) to investigate how to research embodied phenomena, and also how to make sense of the data that is thereby produced, as well as how to incorporate my own reflexively embodied participation in the research field.

Merleau Ponty's theory of perception offers a way of conceptualising the question of what it is to perceive suffering, how different senses interconnect and aid us to make sense of situations. He adopts the view that consciousness is embodied. A perception, for Merleau Ponty, is the way in which the body immediately grasps the *gestalt* of what is going on - or failing to. Our perception takes place as an irreducible whole. Merleau Ponty contests the idea that perception is a process by which the external world is somehow imprinted on the subject. According to him, perception is a behaviour effected not by consciousness but by the body, but not by the body as a piece of the physical world, rather by the body as lived, a living body. Gendlin adapted these ideas to describe the embodied nature of intersubjective encounters:

> *"our bodies sense themselves in living in our situations. Our bodies do our living. Our bodies are infraction in the environment; they interact as bodies, not just through what*

comes with the five senses. Our bodies don't lurk in isolation behind the five peepholes of perception" (Gendlin 1992, p342)

Throughout life, we acquire a vast store of embodiments, from the instinctive rooting of a hungry baby to the lurching dry mouth of a toddler waking from a bad dream, to the first flush of desire for another person, or the bliss evoked by exquisite music or art. These do not simply occur and dissolve but are assimilated into our being in culturally conditioned ways. This repertoire is then drawn upon at different times of life when similar experiences are encountered. Embodiment is recognised as a key constituent both in Bourdieu's notion of *habitus* (1977) and in Merleau Ponty's idea of *body schema* (1945/ 2013). Bourdieu suggests that social reality exists twice: *"in things and in minds, in fields and in habits, outside and inside of agents, and when habits encounters a social world of which it is a product, it finds itself as a 'fish in water', it does not feel the weight of the water, and takes the world about itself for granted"* (Bourdieu and Wacquant 1992, p216). Bourdieu's notion of habitus is a network of sensory and sociocultural associations. Culture and embodiment are related in intimate ways. Consideration of one requires attention to the other. Merleau Ponty's idea of embodiment is linked with his ideas regarding intentionality, and he emphasises the body as *"being-towards-the-world"* (p129) such that its expressions are orientated towards some kind of intended action. Thus, the experience of being in one's body and the way one's body is used to communicate are part of the same body schema.

Observing the nonverbal

A person can convey a great deal about inner experiences through body language, posture, expression and gesture. Gesture, body language and verbal language are intimately associated with inner experiences (Merleau-Ponty 1962). Furthermore, emotional states are not *"psychic facts hidden at the bottom of another's consciousness"* but are modes of behaviour and ways of being that can be seen from the outside. These states exist in expression, they are not hidden behind them (Merleau Ponty 1971, cited Crossley 2001, p84).

Making sense of someone's inner experience through interpretation of gesture and body language is at the core of clinical practice. Lawler defines 'somology' to be an essential aspect of nursing, whereby the body is understood as "*an integration of the object body (the thing) into experience so that it is simultaneously an object, a means of experience, a means of expression, a manner of presence among other people, and a part of one's personal identity"* (2006, p29).

Body language and gesture can be valuable elements of research. Kontos considered that people with advanced Alzheimer's disease are able to interact meaningfully with the world, and that this interaction can be interpreted through observing nonverbal communication. Her research challenges the idea that selfhood is located purely in consciousness, by describing ways in which people expressed themselves in pre-reflective action (Kontos and Naglie 2009; Kontos 2012). Embodied selfhood manifests through appearance, social etiquette, caring, dancing and gesture and describes the *"complex inter-relationship between primordial and social characteristics of the body, all of which reside below the threshold of cognition"* and which are *"grounded in the pre-reflective level of experience, and are manifest primarily in corporeal ways"* (Kontos 2004, p837).

As well as being perceived and expressed through the body, suffering is also recognised through the body. The relevance of this to nursing has been emphasised by Benner (1994) in her conceptualisation of 'embodied awareness' and more recently Draper (2014). Further, there is research that has explored embodied responses to the experience of seeing another person suffering. For example, Benin and Cartwright (2006) observed Disability Studies student's responses to an image of a masked female inpatient in a psychiatric institution sitting in a wheelchair. He described observing visible discomfort of his students as they averted their eyes and attempted to distract themselves from the image. Another study (Hubbard *et al.* 2002) observed how ten care home residents used nonverbal communication. Interestingly they incorporated an additional hermeneutic into their design. Both residents and staff were asked

about the meanings they ascribed to their nonverbal communication. The study highlighted that each nonverbal behaviour could be interpreted in multiple ways.

2.2.4. Recognising suffering is intersubjective

Intersubjectivity refers to the relationship between two or more people and how this is articulated through communication, whether verbal or non-verbal. It acknowledges the fundamentally social nature of interaction.

The best way to ask someone about their suffering is evidently to ask them directly, but this is not without problems (Cassell 1991). People may not recognise their distress as suffering; their comprehension may be beset by misconceptions regarding what is meant by suffering; they may not have the verbal ability to describe their suffering. If suffering is a threat to wholeness it is incumbent on the person observing the suffering to have a sense of what it means to that person to be whole before they can truly understand their suffering. It is clearly impossible to possess this degree of insight into someone's biographical identities, their history and present predicament, their future worries and doubts. We cannot know the 'whole' individual, so we cannot know the precise shape of this 'threat to wholeness'.

I posit that the embodied and idiosyncratic nature of suffering means that efforts to make it objectively measurable will always be thwarted. Although suffering cannot be directly observed as itself, an observer can make inferences based upon observations, interactions, and knowledge, relying on a combination of sensory cues including one's own embodied responses to witnessing the suffering person. To explore how this might be done, I now turn to consider the role of intersubjectivity.

Intersubjectivity

The idea of the 'natural attitude' is an important concept attributed to Husserl (Husserl and Moran 2001). He suggested that our everyday experiences of

objects and encounters are experienced as quite simply ‘being there’. The natural attitude refers to the everyday state that humans are in. Each experience will be situated within a wider, largely unconscious web of facts and presuppositions that are brought to the situation, which inform just how a particular experience impacts on a person in a particular way. The self is never experienced as being separate from the world, and the world is never experienced as separate from the self. Husserl believed that adopting the natural attitude informs reflexivity which can aid in understanding of an intersubjective encounter. For Husserl, this possibility lies in being able to link consciousness and body to create a *“natural, empirical unity by means of which consciousness is located in the space and time of nature, and which, in acts of ‘empathy,’ makes possible reciprocal understanding between animate subjects belonging to one world”* (Moran and Embree 2004, p143)

Intersubjectivity and intuition are important elements of nursing practice that have been attended to in the literature (Gadow 1980; Benner and Tanner 1987; Morse *et al.* 1991). Suffering is not something which can be rationally known. For example, we do not really know whether or not a person in a coma is able to hear or respond to different stimuli or what the experience of dementia feels like, other than through proxy accounts. A few rare narratives of such states by people who have experienced certain states such as delirium certainly illuminate our insight, but they cannot be said to provide insight into the experience itself in terms of how it might affect others. Yet it has been argued that we can intuit some common human experiences such as distress, even where someone is in a situation that we cannot relate to from our own direct experiences. A certain amount of imagination is required if an empathic response can be offered.

The expression of suffering is culturally learned in much the same way as the expression of pain (Zborowski 1952; Encandela 1993). Suffering will present a set of cues, some of which are likely to be socially and culturally conditioned, whilst others may be part of what Ekman has described as ‘universal human expressions’ that include fear and anger (Ekman 1971, 1992; Russell 1994).

Carnevale (2009) argues that a person's appraisal of suffering is likely to incorporate a significant amount of their own emotional sympathetic experience, catalysed by the witnessing of another person suffering. In his account of *einfuehlende Wahr nehmung,* or "empathising perception", Husserl described a *"lived bodily experience in which a felt sense of the other's interiority (namely, my resonating with the other's intentionality) is given to me spontaneously, in a passive genesis of meaning"* (Husserl, cited Churchill 2012, p3). He contrasted the way in which it is possible to pass someone on a street and what occurs when another person is really met, an up-close process that transcends the momentary glance. Heidegger refers to this as *Mitbefindlichkeit*, a kind of involuntary shared attunement consisting of simultaneous recognition, or 'co-affectedness' (Dreyfus and Wrathall 2011).

Hume describes how spectators in an operating theatre become terrified as the fear and anxiety of the patient is transmitted directly to them *"as in strings equally wound up, the motion of one communicates itself to the rest; so, all the affections readily passed from one person to another, and beget correspondent movements in every human creature". The minds of men are "mirrors to one another"* (cited in Baillie 2000, p190). Ekman (2010) considers that in observing suffering, two kinds of empathy are required; cognitive empathy, or perspective-taking is the ability to consciously imagine aspects of the patients' suffering, and affective empathy is a shared emotional attunement that is often unconscious and arises as a result of witnessing suffering in another person. To empathise we need to seek to 'live' in the other person's experience, striking a balance between passive and detached observation (third-person) and complete immersion that would prevent us from disentangling our own emotional experiences from theirs (first-person).

Churchill (2012) argues that since first-person perspectives are inaccessible, and third- person perspectives risk objectifying and reducing personal experiences, we must rely on the resonance created in the interpersonal encounter, or second-person space. In clinical practice we move between first, second and third-person perspectives, venturing inwards when we identify personally with the suffering we witness and moving outwards when we attempt

to analyse the situation objectively. For Churchill, simply acknowledging the existence of intersubjectivity can bring it into sharper focus as an important source of wisdom and insight. He describes the second-person space as living intentionality, or feeling-into the life world of the Other. He adds that this empathising moment from the second-person perspective is a phenomenon that *"happens to us all the time, but we do not think about it, because we do not always put this moment of perception into words" (p3).* Later, he notes that "*If first person research inquiries make us better aware of the interior perspectives and private concerns of both patients and caring professionals, the second person perspective is one that can illuminate the ways in which we as observers have a direct access to the meaning of others' experiences without having to go through the intermediary of first person reports*" (p4).

Observers probably oscillate between second and third person perspectives. At times, objectively observable phenomena may indicate the possibility of suffering and at other times this requires the use of intuition and imagination. An example of observing suffering in the context of this study might look something like this: visual or physiological cues (tachypnoea, tachycardia, restlessness) are identified as an embodied expression of suffering. In approaching the person to 'feel into' what is happening, one is simultaneously engaged in cognitive interpretation of a complex set of presenting signs. These may give rise to an awareness of a sensation of discomfort and restlessness, which is then related to previous experience. This alignment of the sensation of discomfort is associated with a recognition that it is related to the patient's suffering (Middleton-Green 2015).

Although intersubjectivity is a potentially powerful means of recognising suffering, it is also susceptible to being inaccurate, because it is influenced by the observer's experiences and assumptions, and a host of contextual conditions that are not adequately accounted for by Churchill's position because they are likely to act on unconscious levels. Gendlin refers to the 'felt sense', a vague internal body awareness. He distinguishes this from an emotion, pointing out that the latter can usually be easily named (anger, pity, anxiety). A felt sense in contrast is *"vague and murky"* and difficult to articulate (Gendlin 2010, p10). He observes how the felt sense often makes itself known in bodily sensations

rather than abstract thought. Tantia (2014) explores the idea of embodied intuition through in-depth interviews with psychotherapists, in which they described intuition with reference to its associated bodily sensations. She suggests that clinical intuition is largely derived from non-verbal representations, including images, feelings, physical sensations and metaphors.

Reflexivity

There are increasing calls for the use of reflexivity in researching complex social and psychological phenomena. Reflexivity considers the ability of the researcher to consider not only the subject/object of the ethnography but also the position of the researcher. This includes the environment of the researcher and the influence of these conditions on the eventual production of the ethnography.

For example Howes (2006) examined the potential for reflexive ethnography to make use of the emplaced body in order to research being in social spaces. His powerful example of a disabled person navigating a walk to the pub, and worse - the negotiation of travelling from the bar to the table of friends with a round of drinks without spilling them - leaves the reader acutely aware of the emotional and embodied nature of such an experience. Howe suggests that through the use of reflexive ethnography it is possible to gain insights into the experiences of disabled people through careful observation even if one is not actually disabled oneself. A powerful example of reflexive immersion by the researcher is provided by Ruth Behar (2014) in describing her anthropological work on women in Cuba. She describes the experience of having the *"desire to enter into the world around you and having no idea how to do it, the fear of observing too coldly or too distractedly or too raggedly, the rage of cowardice, the insight that is always arriving later, as defiant hindsight, a sense of the utter uselessness of writing anything and yet the burning desire to write something"* (p3).

Multiple interpretations

Ethnography is often used to research rites of passage and transitions, such as birth, death, coming of age and initiation. The context for this study is the liminal place where patients in hospital may be in the last year of life but this cannot be known for sure. They therefore constitute a group of people occupying a zone of uncertainty, in which there may be transitions in identity, shifts in hopes for the future, and re-evaluation of priorities. These kinds of changes do not happen at a fixed point in time but are invariably fluid and evolving. It is therefore important that studying people's experiences of suffering this liminal zone is not restricted to one point in time. The focus is on patients experiencing, not on patient experience. Kleinman's justification for adoption of anthropological principles even when studying topics such as suffering is that although we cannot directly access psychological processes, the ability to view the situation from afar - or the use of "both lenses" - enables the abstraction of process from the contexts of their ethnopsychological meanings (Kleinman, Das and Lock 1997).

2.3 Conclusion

> *"[we ask]…such excited questions as whether the real is truly real and the true really true" (Geertz 2012, p18)*
>
> *"We know much more than we can understand; we are awash in the meanings of experience" (Kleinman, in Jackson 1996, p172)*

Geertz's quote above stems from his account of his journey through multiple incarnations of anthropology over the course of an illustrious career. His reflections in this book, in the twilight of his life (*"so where am I now, as the millennium approaches me, scythe in hand?"*) document the debates that have dominated the field. Such issues include whether objectivity is ever possible, to what degree an ethnographer should be disinterested, and whether knowledge is even possible.

This study required an approach that is sensitive to multiple, nested realities. This means tuning in to the observed events in a scaled way, from the interpersonal context to wider institutional, organisational and sociocultural context. Ethnography concerns itself with the interpretation of cultures, in which

meaning is derived from the practices, symbols and interactions that take place within that culture. Phenomenology focuses more on lived experiences, examining interpersonal realities. Both approaches are important in the current study as suffering is both a social and a personal phenomenon. Recent debate in contemporary ethnography has begun to consider the impact of cognitive science, neuroscience and psychology on the study of culture. In particular, the relationship between bodily and emotional processes that formerly constituted a gap in social anthropology may be addressed. Human behaviour involves the way that people engage sensorially, as well as cognitively, with one another and within their social worlds (Frank 1990; Csordas 1994). Ethnographies of experience need to be able to incorporate a means of approaching the relational and the embodied. People's experiences of suffering are highly personal yet their expression is intersubjective, as is the recognition of one person's suffering by another. It was felt that adopting a phenomenological lens would enable an extension of ethnography to include intersubjective and embodied experience.

Ethnography and phenomenology are naturally comfortable companions, even though they differ in their approach to the subject of study. Both involve taking at face values the views of participants but also probing these assumptions to examine hidden and contrasting meanings. In ethnography, research concentrates on the descriptions that people give of their routines, and the ethnographer typically examines a number of perspectives of the same phenomenon at the same time. Meaning is assigned to phenomena according to cultural interpretation by participants. An interpretive phenomenology, in contrast, examines the chosen phenomenon in relation to hidden meanings that may be concealed in the participant narrative. Phenomenology aims to return to embodied, experiential meanings in order to produce a *"fresh, complex, rich description of a phenomenon as it is concretely lived"* (Finlay 2009, p6). A phenomenological account of suffering aims to find out more about shared meanings of patients' experiences and of the caring practices on the ward.

Adopting phenomenological positions in anthropology is not a new approach (see for example the work of (Jackson 1996; Katz and Csordas 2003; Ram and

Houston 2015). In health research, it has been suggested that a phenomenological approach is coherent within the epistemological framework of ethnography (Maggs-Rapport 2000) and can provide useful depth and triangulation of data, as in a study of care provided by district nurses (Rapport and Maggs 1997) in which interpretive phenomenological interviews with district nurses were supplemented by ethnographically-informed observations. This technique has been replicated more recently (Walshe and Luker 2010) although the latter was from within a realist framework. Nevertheless, both studies agree that combining phenomenological accounts of lived experience deepen and broaden ethnography, whilst ethnography provides a context for the stories that is embedded in the everyday practices within a particular environment.

A synthesis of methodologies also avoids some of the objections to each approach in isolation, as long as there is epistemological commensurability, particularly in research that crosses disciplinary boundaries (Chamberlain 2000). Critics of traditional ethnography have pointed out that in describing shared practices within a culture (the 'emic' view) the individual can be rendered invisible (the 'etic' view) unless there is a robust theoretical foundation (Wolcott 1999). Kleinman (1988) criticises the tendency in medical anthropology to create cultural archetypes and generalisations out of the uncertain details of a person's illness narrative, arguing that cultural representation is just one of many lenses through which lived experience of illness can be explored. Just as medicine can reduce suffering to a biomedical model of pain or other physical pathophysiological state, so too can anthropology be reductive in its analysis. Conversely, critics of phenomenological studies identify that a failure to consider context can create an illusion of individuals and their relationships as existing in some kind of vacuum, representing a bias towards Western notions of the primacy of autonomy and the individual.

The contribution of phenomenology to the current study broadens out anthropology's concern with the social and the cultural to consider the sensate and the temporal. As with anthropology, phenomenology is more concerned with description than explanation, and with reconstruction of a plausible and believable world that can communicate something to the reader. Further,

through continuing careful attention to the lived experience of the individual, the phenomenological lens prevents recourse to grand theories. The ethnographic method is enriched by incorporating philosophical principles of phenomenology producing a method that attends both to the macro context of culture and the meso- and micro- contexts of embodiment, relationality and lived experience - all of which are necessary components of studying suffering.

In this chapter I have outlined the theoretical foundation for the study, recognising the subjectivity of the experience, expression and recognition of suffering. I have rejected research within the positivist tradition and argued for a nuanced, social constructionist approach to the topic, informed by the principles of ethnographic method and a phenomenological approach. I argue that this particular synthesis enables both attention to the embodied and idiosyncratic nature of suffering, and to the broader social and cultural context in which suffering takes place, both of which I argue are indispensable if this study is to address the topic holistically. My methodology was a synthesis of interpretive, phenomenological and reflexive ethnography, which will subsequently be referred to as ‘embodied ethnography’. In the next chapter I undertake a literature review of ethnographic methods, then go on to describe how I developed the study design.

Chapter 3: Embodied Ethnography

3.1 Introduction

In section 3.2 I provide a brief, critical overview of observational studies that have been used to study end-of-life care in hospitals, and/or suffering. I restrict this to observational studies on the basis that I have already established the limitations of other research methods for this topic, and to ensure a pragmatic and coherent review. This literature has informed what is currently known about the context of end-of-life care in hospital, but is largely restricted to studying the practices of healthcare professionals. Much less addressed are the lived experiences of patients. Furthermore, very little research has been conducted on suffering as the primary object of research from this perspective. This gap provides justification for the current project. Section 3.3 outlines the study's design as an embodied ethnography; a synthesis of ethnographic method and phenomenological perspectives. I then describe my method in detail.

3.2 Ethnographic studies of hospitals and end-of-life care

Studies exploring end-of-life care in hospital environments were located by reviewing the research literature in key databases (CINAHL, Medline, PsychInfo and EMBASE) using the following key words: 'ethnography' 'hospital', 'end-of-life care', 'older people' and 'suffering'. Synonyms for these terms were also used, including 'palliative', 'observational studies', 'acute care', 'geriatric'. Searches utilised combinations of terms using AND and OR in order to expand and refine this list. Additional literature was identified by engaging with current research projects via ResearchGate, by engaging with academic colleagues via Twitter and by exploring bibliographies of key texts.

Observational methods have been used to investigate a range of aspects of end-of-life care and hospitals, although it remains a relatively under-utilised method compared to interviews and survey-based approaches (Walshe *et al* 2012). Numerous studies have explored the phenomenon of dying in

contemporary Western hospitals. Renee Fox (1959) undertook a hospital ethnography over a three-year period on a ward in a United States hospital; her work was later published as a book "Experiment Perilous". She was concerned with how sociocultural factors influence medical practice and research. The 'perilous' experiment she refers to in the title of the book speaks of the ethical dilemmas and difficult emotions that arose in the course of her study, in particular those which related to suffering, dying and uncertainty in the context of living with advancing chronic organ failure[3]. Fox's work was one of the first to refer specifically to how death and dying were managed in the day-to-day practices of a hospital ward; she identified how it constitutes a disruption to the ordinary and that the staff have developed ways to routinise practices in such a way as to normalise and contain the difficult aspects of dying.

Glaser and Strauss' (1966) influential study of end-of-life care involved observations across three hospitals in the United States to find out how Americans die. They were interested in 'contexts of action' and focused on the dying process rather than death itself. Their work added weight to the argument that broader societal perspectives on dying influence the structure of care in hospital. Rather than being removed from broader society, hospitals reflect and sustain societal values. They identified that different contexts of awareness of dying shaped subsequent decisions and care. Their study did not explicitly seek to address suffering, and indeed the word is mentioned just six times in their book "Awareness of Dying" (1966) in the following contexts:

1. "snowing patient under to reduce his suffering" (p40)
2. "enactment of pretence becomes harder when "increasing pain or suffering" grow" (p75)
3. "surrender justifiable when suffering is intense and the battle for life almost hopeless" (p84)
4. "reassurances given to patients that their disease does not entail great suffering" (p100)
5. "quotes a nurse as saying, "we can't relieve her pain, everybody wants her to die for her sake, meaning her suffering, we can't even help her"" (p215)
6. "patient is "suffering from excruciating pain"" (p231)

[3] I discuss Fox's work further in chapter 5.

Sudnow (1966) described the professional management of death in hospitals. His study of operational procedures surrounding death further enabled examination of the particular difference between clinical and social death in the hospital organisation, whereby the former refers to what happens to the physical and biological body and the latter describes the process of losing one's role and identity as death approaches.

Rituals relating to end-of-life care have also been addressed in ethnographic work. Wolf (1988) postulated that some nursing rituals are perceived to be sacred (such as laying out the dead), whilst others are profane (such as nursing handover). The hospital is described as imbued with quasi-religious qualities and Wolf describes the process of socialisation of nurses in relation to these rituals, hypothesising that they appear to serve as strategies for staff to manage the emotional sequelae of caring for the dying and the dead.

Mills *et al* (1994) undertook non-participant observation of care of dying patients across 13 wards in four Scottish hospitals. Their study included 50 patients and 150 nurses. Theirs was an account of differences between reported and actual care, and they identified the use by staff of distancing and isolation of patients that increased as death approached [4]Allen's (1996) doctoral study, an ethnography of a surgical and a medical ward in a UK hospital, explored boundaries in nursing work in hospitals. The study referred only in passing to end-of-life care but is mentioned here because it addresses a range of relevant subjects including the impact of body work, inter-occupational boundaries, and the influence of policy on practice.

The idea of a 'good death' was explored in Seymour's (2001) ethnography of the management of dying on an intensive care unit. She observed the struggle faced by nurses in trying to obtain a balance between stopping active treatment and arriving at a shared agreement that the patient is actively dying. This process entailed a shift from body work to emotion work, as nursing care came

[4] Their paper reported on observations conducted in 1983 but that remained unpublished until 1994 because of the death of one of the authors.

to be recast in spiritual and comfort terms rather than biomedical, once this transition had taken place. The emotional labour of nursing - a phenomenon widely addressed in the nursing literature - was a significant factor in these struggles, according to Seymour.

Costello (2001) explored the experiences of dying and death on an elderly ward in a UK hospital, identifying a lack of emotional engagement with patients about the issues that were facing them. His study specifically focused upon practices of nurses, with observations being used in the development of a semi-structured interview schedule and analysed using a modified Grounded Theory approach. In this regard, the study was not strictly speaking an ethnography but has been included here because of its focus on people dying in hospitals. He was interested to find out how doctors and nurses develop and maintain disclosure norms, and how ward cultural practices influence nursing care. He identified a range of obstacles to effective care, most of which related to difficulties in communication. He found that care was often characterised by a lack of emotional engagement with patients, coupled with institutional non-disclosure of honest information about death and dying. He reported that when interviewed, nurses described their work in terms of holistic care, incorporating psychological and spiritual care, but that when they were observed they attended primarily to physical needs. His study also highlighted the influence of power relations between nurses and doctors on the negotiated priorities of care, portraying patients as relatively voiceless in this process. Costello's study provides important insight into the context of care for the current study although since it focused only on nursing practices it omitted the influence and impact of the multiprofessional team. Further, it did not explore in detail the experiences of the patients individually, focusing rather on the nursing practices that defined end of life care.

Chapple (2010) undertook an extended ethnography of two hospitals in the United States. Her study suggested that the geographical layout of hospital wards, combined with the biomedical ideologies that shape care, means that for those people who die in hospital privacy is often compromised. Further, decisions in care can be confused because care of the dying is delivered

alongside care of the recovering. Kaufman's (2005) investigation of end of life care in hospital examined ways in which advancing medical technologies have led to a situation in which the boundaries between alive and dead are increasingly blurred - a so-called *"zone of indistinction"* (p62).

A reflexive journal written during an ethnography of palliative and aged care environments in Sweden (Edvardsson and Street 2007) was used to examine issues of embodiment in healthcare ethnography, highlighting that sensory data can supplement and illuminate the experiences of care by patients. This paper identified the importance of considering the contribution of the senses to ethnography, but was largely reflected upon for the purpose of drawing comparisons between the hospital and hospice environment rather than to engage on a deeper level with the patients' lived experience. The sensory aspect of the study was an aside, and its main findings have not been reported upon in the literature. The impact of the environment on patient care was not explored in the paper.

Manderson and Warren's (2010) ethnography of older people undergoing rehabilitation following amputation identifies differences in perceptions between the patients and the staff with regards to what constitutes rehabilitation. They suggest that a culture of positivity is utilised by staff in order to buffer themselves against negativity related to the frequent poor outcomes of rehabilitative attempts for this group of patients.

Porock *et al* (2009b) observed people dying in a British hospital and explored the extent to which they were afforded privacy during the dying process, with *"the final scenes of life played to an audience of strangers"* (p11). The study, carried out on a single ward in a UK hospital, demonstrated that the public nature of dying shaped the behaviour of visitors and staff alike, inhibiting the expression of difficult emotions.

Coughlin (2013) observed episodes of care during periods of hospitalisation and explored patient and nurses' perceptions of the key events during these periods. By comparing the observed events with the accounts provided by

patients and nurses, she was able to demonstrate a discrepancy in perceptions. She suggests that patient care may be enhanced by seeking to narrow the gap between staff perceptions and patient perceptions through clarification with patients and their families. Bergenholtz *et al.* (2015) explored the culture of palliative nursing care in hospital medical wards in Denmark, identifying multiple ways in which the ward environment influenced care of the dying. For example, the architecture and equipment of the ward was observed to prioritise treatment rather than peace and dignity. Transitions to palliative care were found to take place relatively late in the illness trajectory. Most recently, a Canadian study (Chan *et al.* 2017) used a focused ethnography to present how the existing 'logic of care' informs a system of prioritisation on hospital wards where people who are dying are cared for alongside people who are being actively and sometimes aggressively treated. Care of the dying is often afforded a relatively low priority within this logic of care as the pressing forces on staff are those that save and prolong lives. Other studies have identified that nurses often feel ill-prepared to care for dying people (Hopkinson, Hallett and Luker 2005; Bloomer *et al.* 2013; Chan *et al.* 2017).

In comparison to the rich body of ethnographic work on end-of-life care and hospitals, few ethnographies attend to suffering. An exception is Kleinman's work examining the experience of pain and suffering across different cultures (1981, 1988). By including the voices of people living with different illnesses, he produced a rich depiction of context which has been an important influence in medical anthropology. Later work extended to explore the idea of social suffering within the clinical context (Kleinman *et al* 1997). His work did not, however, extend to examine suffering in people in hospital; nor did it include those unable to tell their stories.

3.2.1 Critique

The overview of studies described above provide valuable insight into the context of care for dying people in hospital. However, the review also demonstrates that there are some unaddressed issues in this literature to which this study can contribute. The first relates to the lack of inclusion of patient experience, with some notable exceptions (Glaser and Strauss's observations

of patient and family awareness of dying, for example). The majority describe the healthcare practices that shape care of the dying or other hospital practices. The experiences of people dying with dementia, for example, are excluded from their participants. Secondly, none of the studies address the issue of suffering explicitly in the context in which we are interested. The only ethnographic work to attend to suffering directly is that of Kleinman, and this has not been in the context of hospital care.

3.3 Method

This section describes the design and conduct of the study. I describe and reflect upon the extended process of obtaining ethical approval. I then present a reflexive account of how the fieldwork and analysis was carried out, including some of the influences that became apparent during the process of observation. Finally, I consider the issue of quality assurance in ethnographic work and describe how potential concerns have been addressed.

3.3.1 Ethics: A Reflection

Before I could conduct my study, I needed to gain ethical approval and research governance permissions. The study was granted ethical approval in January 2015 by Leeds West Research Ethics Committee (REC Ref: 14/YH/0166 IRAS ID: 149772, Appendix 1). It was also necessary to obtain approval from the local Acute Hospital Trust Research and Knowledge Department, which involved submitting a replicate set of data via the IRAS website which centralises all NHS research ethics. This protracted and complex process took nine months in total and four revisions were required. Many ethical issues and concerns were raised by the panel, but in the event, none of the scenarios of concern arose during the study. However, there were multiple ethical issues that required attention during the course of the study that had not been anticipated by the panel, despite the protracted and detailed process of approval. In Appendix 2, I reflect further upon this, suggesting that since NHS Ethics Panels primarily

evolved to address risk in biomedical research they do not necessarily address the kinds of specific ethical challenges that arise in observational studies[5].

Ethics must become capable of taking both local, networked, moral experience and universal, transcendent ethical ‘standards' into account (Kleinman 1999, p69). Parker (2007) suggests that in failing to pay attention to culture, the application of ethical principles to research risks being insensitive to the object of research. In identifying that the word ‘suffering’ in the participant information literature could itself cause distress (one of several issues I have written about in Appendix 2) it could be argued that the panel were themselves influenced by the same broader societal concerns identified in the literature review that provided the motivation for the study itself; namely, that emotionally salient and intangible notions such as suffering are both central to the experience of dying people, but also invisible, ignored and feared within the biomedical paradigm.

Kleinman suggests by careful documentation and thick description of the ways in which people live in their worlds, any ethical issues that arise can be understood in a more nuanced and contextualised way. This does not mean that moral ethnography is straightforward in terms of deciding on the ‘right’ course of action but it does offer a naturalistic perspective within which people’s actions can make sense in relation to their own world view rather than to an abstract or universalised ideal. He cites the following example to illustrate this point in a semi-fictional anthropological novel, “Return to Laughter”:

> *Bowen describes her experiences of observing a participant “Amara” who was dying in childbirth, and who was being treated with a range of magic and ritual interventions. Bowen described her frustration and sadness at watching what was about to be something she perceived to be a preventable death. Eventually, in a burst of emotion, she told the attending healers that if they*

[5] This was presented as a workshop in 2016 with Andrea Capstick, my academic supervisor. For more information see *http://2016.oneverydayethics.co.uk/presenters/andrea-capstick/*

wanted her to live they must move her at once to a hospital where she could have surgery. She even went so far as to offer to arrange the transportation herself. In the event, both the participant, her family and the healers declined her offer and Amara died. "In silence and bitterness, at nightfall, [she] left." (Bowen 1954, cited p185-185 Kleinman 1999)

I had anticipated situations in which I might have an ethical responsibility to intervene and indeed there were several situations in which I did so (these are discussed further in chapter 9). The question of whether or not to intervene has been addressed in nursing ethnography (Costello 2001) and there is consensus that each situation must be appraised in relation to one's accountability both as a researcher but also as a registered nurse.

In **Phase 1** which lasted for approximately two weeks, I observed the care structures and processes on the ward through working alongside different members of the health and social care team. In **Phase 2** I spent time with individual patients over more prolonged periods of time.

3.4 The Fieldwork

3.4.1 Phase 1: Observing the Ward Routine

The purpose of Phase 1 was to gain familiarity with the general ward routine and to build rapport with staff. For this I used observation and occasionally supported staff in assisting patients with basic activities such as washing and eating. For this study, I have named the ward "Bluebell Ward", and the fictional location of the hospital "Canroyd".

Participants

Participants in Phase 1 of the study consisted of every patient, visitor and staff member on Bluebell ward during the times when I was observing. As far as possible I had made my presence known: through numerous visits to the ward prior to the study, by placing leaflets and posters on the nurses' pods, in the doctor's room and on the staffroom board. I explained in brief the reason for my

presence to anyone who seemed to want to know. I did not, however, make a point of doing this with everyone on the ward. Practically, this would have been impossible and the Ethics Panel were satisfied with an opt-out mechanism, whereby all participants were offered the opportunity to opt out of being observed, or to request that I delete any data related to observations involving them during this first phase of the study.

Recruitment

After initial engagement with the gatekeepers (ward sisters, consultants and matrons) I arranged a series of visits to meet the staff and appraise them in relation to the planned study. These meetings were brief as I had been scheduled into the crossover time between early and late shifts. This meant that there were more staff on Bluebell Ward than usual, but this was a particularly busy time and staff were often called away to attend to something. It also only enabled me to engage with the nursing staff (healthcare assistants and registered nurses). Having discussed the structure of the MDT[6] with the sister, I learnt that many of the allied health professionals who were likely to be in attendance on the ward were based elsewhere, had responsibilities throughout the hospital, and work as part of much larger teams across the patch. In order to recruit these participants, and any others who were unaware of the study before arriving, I sought them out individually as they arrived on the ward and explained my role to them at the earliest opportunity.

In terms of the patients and visitors, I adopted the same approach. When I was observing normal everyday care on the ward, I explained my role only if it felt relevant, for example in the case of one patient (who subsequently opted out of the study) I sensed that my presence sitting on a chair in the corner of the shared bay may have been a potential source of distress. I therefore introduced myself by name and explained that I was there in the capacity of being a researcher, and was spending the week getting used to what all the different health professional's roles were on the ward.

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[6] *Multidisciplinary Team*

Consent

Consenting was a continuous process, not a single event. It was not possible to predict particular issues that may arise in the course of the study.
Information was provided to staff participants in the weeks prior to commencement. Posters were displayed with basic information and my contact details, as well as dates and times that I would be on the ward to introduce myself and answer any questions. These times were scheduled in order to make these sessions accessible to staff on early, late and night shifts.
Information sheets were distributed to all members of the multidisciplinary team, one month prior to the study, including an opt-out slip if they did not wish to be observed. During the period of observation, at the beginning of each shift, I planned to attend the handover meeting in order to remind staff of my presence and provide further opportunities for them to opt out of the study.

Staff members, including those who had not signed the opt-out form, were made aware that they could ask that observation be stopped at any time; no reason was required. For healthcare professionals who were not core staff, for example physiotherapists who visit the ward, consent to be observed was sought as soon as practical, ideally prior to the episode being observed, but where this was not the case immediately afterwards. For this purpose, I held a folder of information sheets and opt out forms as it was never possible to predict when I would next meet a participant.

For patients, consent was not sought for Phase 1 of the study as they form part of the research field and patients or carers were not asked any specific information during this phase other than that derived through normal social interaction. In addition, no personal patient-related information was gathered during this first phase of the study.

3.4.2 Phase 2: In-Depth Case Studies

The purpose of Phase 2 was to explore individual patient's experiences, focusing more specifically on the phenomenon of suffering.

Participants

Phase 2 involved an in-depth case study approach in which patients were recruited as participants using a purposive approach. By sampling purposively, I could seek out diversity in the sample. Given the comparatively brief time in the field, it was necessary to obtain a depth of insight into individual experiences, requiring extended periods of one-to-one contact. On the other hand, the idiosyncratic nature of each patient meant that a smaller number of case studies would reveal less in the way of patterns and themes that could be understood in a way which could offer something of use in other areas of practice. I therefore decided to approach all patients on the ward who I perceived to be potentially in the last year of life.

Inclusion Criteria

1. Prognosis: person is thought to be in the last months of life

Patients invited to participate in Phase 2 were those who I considered to be potentially in the last months of life. I decided not to purposively seek out those patients who I or the staff considered to be suffering as this felt as though it would pre-determine what suffering was considered to be. The key criterion was that the person was diagnosed with a clinical condition that was no longer responsive to curative intervention, and their prognosis was thought to be limited to weeks or months rather than years. Prognosticating was not as easy as I had anticipated. I was aware from the literature that transitioning from curative to palliative care is a challenging problem in clinical care (Gott et al. 2013; Broom et al. 2015). Potential participants were initially identified through listening to nursing handover but because prognosis was rarely explicitly discussed at this time it was necessary to make use of clinical experience. If I heard staff discussing a patient who sounded as though they may reasonably be in the last months of life I would follow this up with questions to further clarify, such as their current renal function, recent hospital admissions, other illnesses, and the health professional's own opinion as to whether or not the person may be approaching death.

Individual patients were identified through conversations with staff and patients. Sometimes it was necessary to consult the patient's medical notes in order to ascertain whether they met the inclusion criteria.

2. Communication and capacity: person may have cognitive impairment or other communicative difficulty

Many older patients on hospital wards are unable to communicate verbally. This may be a result of cognitive impairment, as in the case of people with advanced dementia. Alternatively, it may be a consequence of being seriously ill, when levels of consciousness were often reduced. As discussed in chapter 2 my chosen method needed to allow for the study of interpersonal encounters between people unable to communicate verbally, and those who were caring for them. Indeed, those unable to speak constitute a group often omitted from research or evaluations; their experiences were often reconstructed through research with staff or via proxy voices such as relatives and carers (ONS 2012). People with advanced disease are often omitted from research because it is considered to be an additional and unnecessary burden (Lee and Kristjanson 2003). However, it is ethically important to involve people at the end of life in research in order to gain more direct understanding of their experiences (Gysels *et al.* 2013) and furthermore, people with advanced disease often express a desire to help through participating in research (Gysels, Shipman and Higginson 2006). I therefore purposively selected some participants who were unable to communicate to be part of the case study group.

Recruitment

I approached 28 patients identified as meeting the inclusion criteria, from whom there were sixteen patients whose direct or consultee consent was obtained. All patients who I perceived to be potentially in the last year of life were invited to participate. A total of sixteen patients were eventually recruited, utilising direct or consultee consent. Although there were more patients probably in the last year of life, there were limitations on recruitment because of various reasons: (1) lack of capacity and no appropriate consultee, (2) excessive distress, (3) declined to

participate, (4) consultee too distressed and (5) staff opinion that recruitment was inappropriate.

Consent

Consent issues for this phase relate to both staff and patients. For patients, this was carried out in 3 stages:

1. Assumption of capacity unless otherwise known; assessment of mental capacity in accordance with the Mental Capacity Act (Department of Health 2005) in relation to understanding requirements of participating in study as outlined on Information Sheet.

2. Providing and explaining to patients with capacity the core information about the project in an appropriate way and gaining their written informed consent, or where the patient does not have capacity, following an appropriate process (see below).

3. Ensuring relatives were also aware of my role.

Patients able to give consent were provided with information about the study and a consent form. For patients without capacity, relatives were approached to act as consultees and provide a perspective on whether, in their opinion, the patient would have consented if able, in line with current guidance (Department of Health 2008b) based on the Mental Capacity Act (HMSO 2005). In one instance where no family member was available, a member of the team acted as consultee. Staff were provided with the information sheet, numerous opportunities (staff meetings and opportunistic conversations) during Phase 1, so that consent for Phase 2 was in place by the time it began.

3.4.3 Method

Between June and September 2015, 186 hours of ward-based observation were carried out. Additionally, 18 hours of observations of other hospital activity

were conducted, including education sessions and meetings. Observation spanned one month for the ward-based study, and a further two months for additional visits. Observation took place in blocks of time ranging from one hour to 14 hours, and was undertaken at different times of day and night and on different days of the week, including weekends. This was to ensure a representative range of data and events were included (Hammersley and Atkinson 2007).

3.4.4 Gathering Data

My role was that of a participant-observer (De Munck and Sobo 1998) and at times I would assist the healthcare assistants to support patients with basic care needs or give out meals and drinks. This enabled an establishment of trust and rapport and gave me rapid insight into the activities of my participants (DeWalt and DeWalt 2002; LeCompte and Schensul 2010).

The title of ‘data collection’ sat a little uneasily with me. It implied a shopping trip or a nature forage of sorts. I never felt as though I were collecting ‘data’. I found myself discussing things with people, reflecting on how the environment was making me feel, writing down these thoughts, fragments and disconnected sparks of ideas. It was in the reconstruction, after each shift, as I sifted through these fragments, that I began their reconstruction. It was only in the writing that they became intelligible ideas, and these ideas then accompanied me back to the field the following day and were further explored, turned over, digested and enriched. This didn't feel as though I was merely scooping up something that already existed, in some kind of external reality, waiting for me to assemble into a thesis. It was an iterative and interpretive approach. Ethnographic ’data’ is not something that is passively given up by the field when the latter is interrogated by the researcher, yet in terms of research ethics language is treated in much the same way as might be applied to a blood or tissue sample, or questionnaire. Indeed, a core tenet of ethnographic practice is in the process of mutual engagement through which the ethnographic stories are generated. There is an ethical imperative that the participants must benefit from their involvement, whether through enabling and empowering them to gain a deeper

understanding of some phenomenon, or through being able to articulate a narrative that may otherwise go unheard.

My field notes consisted 'brief-but-vivid' observations (Mason 2002), notes on embodied responses and reactions, descriptions of non-verbal communication, descriptions of the physical environment, and micro-narratives. For the latter, I used a form of shorthand in order to capture the interactions as faithfully as possible. Part way through the fieldwork I realised that the data collection could be enhanced with photographs, so I sought and was granted a major amendment to my ethics approval to permit me to take photographs of spaces and objects, no identifiable people or other features were to be included. These photographs were authorised with the nurse in charge and any identifiable details were amended using iPhoto software.

Participant observation

> *The more a field worker knows and is known, the less that field worker can avoid joining the action. The other side of this is that the less field worker knows and is known, the greater will be that field worker's inability to interpret the actions of others, whether those actions taken into account or not (Tedlock 1991, p287)*

Malinowski (1932) is one of the first to have been credited with the development of participant observation. In his study of village life on the Omarkana Trobrian Islands he described his morning routine:

> *"I would get out from under my mosquito net, to find around me the village life beginning to stir…As I went on my morning walk through the village, I could see intimate details of family life, of toilet, cooking, taking of meals; I could see the arrangements for the day's work, people starting on their errands, or groups of men and women busy at some manufacturing task" (p7-8)*

Participant observation provides the lens through which the field is observed. It relies on the development of a relationship with participants, and this enables investigation of practices at a much deeper level than if they were purely observed.

Participant observation is not without challenges in this setting, where true 'participation' as either a professional or a patient is not actually possible. Fox described how she was introduced to a newly admitted patient to the ward: *"This is Miss Fox. She is not a doctor exactly. She is not a patient exactly. But she falls somewhere in between"* (Fox 1959, p234).

In undertaking participant observation, the first task to be addressed was in the establishment of rapport with participants. Once in the field, maintenance of relationships required ongoing attention; at times, it can be a case of striking a balance between proximity and distance. Too close and one loses perspective or takes on emotional attachment to particular people or outcomes; too distant and the subtle content of emotive issues may not be visible. Relationships built on trust were essential, and it was clear that - although it did diminish over time, there was a certain amount of edginess among some staff regarding being observed. I was in no doubt that this was related to the extent of the regulation and monitoring that they were exposed to on an ongoing basis. The following extracts illustrate that despite friendliness and receptivity there were also undercurrents of ambivalence relating to my presence:

> *3:30am, the patients are asleep - or quiet, in any event. A healthcare assistant and nurse are looking at a computer screen and shopping for handbags. "I hope you're not going to report us to Panorama" giggled one of them.*

My level of participation was comparatively high at the beginning. I would assist staff to help patients wash and dress and carry out other activities. I would give out meals and sit with patients while they ate. I would run small errands for staff which gave me opportunities to get to know of their relationships with other parts of the hospital. As the fieldwork progressed and I began to spend more

time with the patient participants, my level of participation reduced and my role became one of primarily observing – either by walking alongside staff or patient, or sitting by bedsides.

Walking

In ethnography, it has long been recognised that “walking with others” enables the development of empathy and affinity with the participants of the research. In this study, I adopted three modes of being in the space. In the first, I did not attach myself to any particular participant but would sit in a particular location and observe whatever happened. In the second mode of being I walked alongside different professionals, either the ordered, regimented round of the medics, or the busy morning of “cares”, or the drug round, or accompanying a nurse as she responded to a call bell, or alongside a patient for the few who were able to walk. In the third mode of being I remained still. I sat near the patient's bed - sometimes for up to 6 hours - observing each and every interaction that took place. During the time between interactions I would either talk with them or simply sit and observe the various sensory experiences that this stillness offered. Walking with other people can create a particular insight into activities that is related to more than just the pace of the walk (Ingold 2011; Pink 2015). Bourdieu considered that the actions of the body reveal ways in which the person locates themselves in the world – an embodied habitus that becomes inscribed on the body through conditioning (Gale 2010).

Stillness

As I became accustomed to the staff routine and made the shift into Phase 2 of the study, I decided to spend less time walking and more time sitting – alone, and with patients. Over the next week, I spent a lot of time on the row of padded chairs opposite the “dirty utility” room, from which vantage point I could see most of the corridor, although not into any patient rooms. Sometimes I was joined by a patient or member of staff for a time. At other points, I asked patients whether they would mind if I sat near them for a while. I was greeted with a range of responses: bemusement, gratitude, and indifference (from the patients), and curiosity, ambivalence and irritation (from staff). But this new way

of observing provided me with much more space to observe; when sitting, I didn't need to make decisions about who to follow.

Researching the Familiar

As a nurse, I already hold a view with regards to the nature of suffering, its causes and manifestations, and those facets of the field that might influence suffering. My perspectives on illness and health, and how these interface with culture, have developed over many years initially through medical training, and then nursing training. Over a decade caring for dying people I have heard stories about their journeys through healthcare and their hospital experiences. As an educator, I have listened to countless stories from my student nurses about practice and care of older people in hospitals. However, other than as a student myself, I have never worked in the acute care environment, so it is at once familiar and unfamiliar.

Much has been written on the experience of being a nurse, undertaking research in a familiar context (Cudmore and Sondermeyer 2007). Becoming aware of competing agendas between professionals and institutions has led some researchers to identify that different aspects of their clinician/researcher role came to the fore in different circumstances (Walker 1997, Cudmore 2007). Seymour (2000) found her history as an intensive care nurse valuable when researching the dying in this setting, because she perceived that it meant she did not need to spend extended periods of time familiarising herself with the complexities of care in that very technical environment. Cudmore reflects that as an emergency nurse, there were challenges in maintaining the required distance to undertake research without also acquiring the judgment from participants that one is an 'outsider', which she considered impaired the level to which they were willing to disclose certain aspects of their practices. There is consensus in the literature that this brings both benefits and challenges, and certainly my experience reflected this. Bluebell Ward[7] was at once familiar and unfamiliar; caring for chronically ill and dying older people is something in which

I have experience, but I have not worked in a ward environment for a decade. Further, it is recognised that researching one's own practice can lead to reluctance to portray aspects of negative practice, or a 'crisis of representation' (Guba and Lincoln 1994) which risks bias in the final write up. However, this was mitigated to extent by presenting ongoing findings back to staff from Bluebell Ward on an end-of-life care study day held in the hospital and organised by one of the consultants. Staff were quick to engage in discussion about the challenges of working in this setting and in particular caring for people who may be at the end of life and were accepting of poor practices as something they were both aware of and had a desire to improve.

Other challenges included the possibility that in trying to identify 'taken-for-granted' practices in the nurses, I (as a nurse) might also take them for granted and not notice them. Further, my identity as a palliative care nurse means that I have internalised values pertaining to palliative care, just as the nurses on the ward have been socialised in acute care. Resisting the temptation to be critical often meant reminding myself regularly that this was a different environment of care, with different priorities. Other challenges arose included occasionally slipping into nurse-mode, for example through adopting a problem-solving approach to a patient predicament, or advocating on a patient's behalf when on the doctor's round.

Overall, however, my dual identity as a nurse was a benefit rather than a hindrance. It was not necessary, for example, for me to interrogate or interpret the multiple uses of acronyms and jargon that constitute the daily talk between members of the team. I also did not need to undertake extensive background research into the prognostic trajectories of the various diseases I encountered, nor the medical records or medications. One nurse commented that she had been relieved when she found out I knew about nursing - *"I thought I was going to have to explain every little thing"* she told me.

Identifying the Object

The researcher as observer will always be selective; it is possible to filter out extraneous information in order to pay attention to that which is considered to be most relevant to the task in hand, or most threatening, or most surprising (see Kahneman 2012 for more on bias in perception). There is no simple solution to this; efforts to minimise bias through the use of reflexivity, bracketing, or other devices, are fundamentally flawed. How, for example, might a disclosing account of emotions and influences convince a reader that the study is free from selectivity? The busy environment of the ward was often a seemingly chaotic maelstrom of events. Multiple conversations took place simultaneously and there was usually more than one patient who fulfilled my inclusion criteria who was amenable to observation at any one time. At times, it was difficult to decide where to be. This became easier with time; nursing handover at the start of each shift was an opportunity to identify situations where there were particular issues arising in relation to patient wellbeing. I observed encounters where I knew there were difficult decisions or conversations that needed to be had, as these often related to key decisions relating to continuing, withdrawing or withholding treatment. This was to become a key theme in relation to iatrogenic suffering (see chapter 9).

The field notes reveal multiple decisions that were made in relation to who to observe, and illustrate that this decision was made for the following three reasons:

1. Pragmatic:

> *"The ward is busy as usual. The nurses at Pod 1 are preoccupied with the new admission who requires 'a load of things sorting'. I don't want to get in the way. I walk past room 2 and there is a woman in a dark blue dressing gown sitting alone in the high-backed plastic chair, chin resting in her hands. I go in"*

2. Ethical:

> *“Sheila is crying and calling out. She taps her empty plastic mug on the bars at the side of her bed. Sometimes the calling increases in volume to a scream, and sometimes this upsets other patients and visitors. I imagine it also upsets the staff. But when somebody enters her room, she half sits up, her hair wild and her hospital gown twisted. She crinkles her eyes to focus and see who has come in, and as soon as she recognises someone she smiles. I decide to sit with her for a while.”*

3. Staff request:

> *“I arrived for the night shift, make a cup of tea and walk down to Pod 1 to sit and hear handover. I sit with Katie. She tells me Cheryl wants to work with me tonight on Pod 3. I am taken aback. It is the first time I have received instructions. I don't know any of the patients down there and feel a flash of resistance, but then reflect that it will give me a chance to see some different things, work with a different nurse. I'm also aware that by now I know Kirsty and feel comfortable with her, as she does with me. Cheryl, I don’t quite have the measure of yet. But we'll see.”*

3.4.5 Reflections in the field: Performativity

Goffman (1967, 1971) suggested that the field of social interaction could be compared to a theatre, and that people within that field could be compared to actors who play a variety of roles according to circumstances. He employed principles of dramaturgy and applied them as a lens through which to undertake sociological study of everyday interactions in a mental health institution, exposing the kinds of social roles and rituals that are played out between people (actors) who adopt particular roles in a particular setting, and ways in which negotiated processes can be observed in real-life situations. Bauman observes that *“personal narratives are merely rehearsals of public rhetoric designed by the public media to ‘represent subjective truths’”* (1992, p86). He is

speaking of the inauthenticity of the *"alleged authentic self"* that is covered up by *"spectacles of sincerity"*. The aspect of his theory which bears relevance to the current study is the difference between 'on-stage', 'off-stage' and 'backstage' performances. On the ward, it was possible to identify examples of where and how these contexts of interaction arose. Meaning could be assigned to actions through performance - and meaning could also be attributed by the audience.

My presence seemed to influence the ways that staff acted - or at least the ways that they *said* they acted. Certain aspects of practice were emphasised in my presence, whilst others were de-emphasised. This indicated to me that the staff member was conveying to me something of what they felt was important. It also hinted at how they conceptualised compassionate care in the aftermath of the Francis Report. The scripts seemed to be manifestations of a felt need to portray the ward in a good light. Interestingly, this pressure was conveyed most keenly by the healthcare support workers and the consultants. The rest of the staff participants, such as the nurses and the allied health professionals, more readily described the challenges that they perceived. They perhaps viewed the research project as a chance for them to describe the complexity of their clinical area, which they believe to be misunderstood, and to simultaneously demonstrate how hard they work. Alternatively, because we had a shared professional background, the ease with which nurses confided in me may have been greater than for those from different professions.

Over time in the field more trusting relationships evolved and staff began to confide more in me about the true nature of their work and the tensions that they felt. This strengthened my sense that those early performances had served an important function in terms of this research, in telling me what staff were trying to convey to me about the work that they did. I briefly consider two of these scripts, using illustrative examples from the fieldwork.

Multiple rules governed daily practices on Bluebell ward. Some of these were explicit – such as the requirement for a dying person to be commenced on the Care of the Dying Care Plan. Others were subtler, and could only be perceived

when a member of staff intentionally or inadvertently broke those rules. The culture of an organisation gives its members the sense of stability and order, and imparts meaning to their daily actives. Organisational culture refers to the *"system of assumptions, values, norms and attitudes, manifested through symbols, which members of one organisation have developed and adopted through mutual experience, and which help them to determine the meaning of the world surrounding them and how to behave in it* (Janicijevic 2011, p72). These rules, and the micro-cultures in which they were adhered to (or not), gave rise to particular types of performance.

"Look How Compassionate We Are"

I became accustomed to tailoring how I describe my study, according to whom I was speaking. As soon as I mentioned the word 'compassion' the ward clerk described several ways in which care on the ward was compassionate. She described their monthly cake sale, to raise funds to buy toiletries for patients who come in unaccompanied or who have no visitors. She was at pains to point out to me that this was not covered by the NHS, with a tut, and a roll of her eyes. She told me how caring the nurses were. She showed me a wall full of 'thank you' cards from relatives.

Healthcare assistants had their own script to show me how compassionate they were, as the following excerpt illustrates:

> *Edith comes in, talking loudly - "your soup for you, because you like it, don't you?"*
>
> *Patient: "Can you raise it?"*
>
> *E: "I can raise it any way you want"*
>
> *Pt: "A bit higher"*
>
> *E: "I don't think it will go any higher"*
>
> *Pt: "Oh, it's okay then"*
>
> *E: "Are you sure"*

E: "Right, then, I'll leave you to have your dinner"

(then to me as she leaves, smiling): "Ah, he's lovely, isn't he?"

The idea of smiling as indicating compassionate care can be seen in the government report "Compassion in Practice: One Year On" which was published a year after the Francis Report. "*Compassion* [the report suggests] *is represented in many ways including a word, a smile, an act of kindness, or by listening to another person. It is an experience in which one person recognises and responds to the suffering of another person by giving emotional energy"* (NHS England / Nursing Directorate 2013, p8).

Glaser and Strauss recognised the existence of 'emotion work' in care of the dying, but this theory was developed more deeply by Hochschild's (1979) subsequent study of the management of emotions in certain professions. Hochschild was influenced here by Goffman, suggesting that emotional labour is required of certain professions but that in order to adequately fulfil the role it is usually necessary to 'manage' this emotion, part of which requires the ability to act as though one is feeling an emotion when this may not be the case. All that is required, Hochschild suggests, is that the recipient of the emotional interaction believes that the emotion is authentic. To this end she describes that actors are required to suppress or induce emotions in order to convey what is thought to be commensurate with the role. Thus a worker's smile can be *"on them but not of them"* (Hochschild 1983). Although her work focused on public service employees such as airline attendants and debt collectors, her ideas have been applied widely within nursing (James 1989, 1992; Kelly *et al.* 2000; and for a review: Badolamenti *et al.* 2017).

Hidden Performance: Compassionate Care

Not all staff were at pains to tell me how compassionate they were. Sometimes I observed what I would describe as compassionate care; that which was conducted without expectation of being observed, which was additional to what was required in the list of tasks to be completed, and which was carried out in a particular frame of mind. This is perhaps best conveyed in the excerpt below in

which Alvar, a new nurse who recently moved to the UK from Portugal, was with a dying patient in a side room. The door was closed, and as I entered I observed the following:

> *Her family have gone home and her light has been turned down low; I can hear her breath, rasping. Alvar is leant over her; with a piece of soft gauze and a plastic tub of warm water he is gently and methodically wiping the crusted blood and mucous from her nostrils, lips and tongue. She is not responding - her tongue is swollen and her eyes bulge. The swelling in her arms has worsened and her skin is shiny, mottled, cold. I stand in silence and watch. He does not respond to me other than to acknowledge my presence with a nod. I sit in silence as he continues. Then, some moments later, says "there are two kinds of nurses, there are those who spend an extra five minutes after the main jobs are done and those who don't. When my grandfather was dying, I noticed this". He dabs Vaseline on to her lips. "When people are old, it's organic, natural. The body starts to fail. It is natural. I could never do paediatrics because that is not natural. She is not suffering now".*
>
> *It's the fourth day of my observations, and the first time I have heard the word 'suffering' mentioned. I look at the patient, her skin smooth and her lips soft again.*
>
> *"No", I agree, "she is not suffering".*

Informal interviews

I spoke to participants about a range of topics, not just suffering. Interviews were usually brief and took place at a range of locations on the ward, by the patients' bedside, in the day room, in the kitchen, at the nurses' station. Questions were often catalysed by observations and these interviews would often be aimed at gaining a deeper understanding of particular events that had been observed. In accordance with Spradley's (1979) notion of the 'ethnographic interview', questions included a combination of descriptive (for

example, *“can you explain what you are doing?”*), structural (for example, *“what do you do when patients are admitted?” “What do you like / dislike most about your work?”)* and contrast (for example, *“what’s the difference between how end of life care happens for people with cancer and without?”*) items. Sometimes this involved postulating hypothetical scenarios. Other verbal interaction was captured by observing and documenting using a form of shorthand the main elements of the conversations.

Examination of documents, objects and spaces

Patients' medical and nursing notes were scrutinised in order to build up a history of their illness and a sense of their previous involvement with the hospital and other services. The notes also served to illuminate the roles of the various members of the team and offered insight into what the team considered to be the most important elements of the patient picture. Additionally, ward and hospital documentation including policies and protocols, displayed guidance, posters and publicity were included in the documentary analysis.

3.4.6 Analysis

Over 200,000 words of field notes were gathered. The sample included 16 patients, 7 family members and 42 members of staff (see appendices 3 and 4). Some of these were detailed descriptions of elements of the environment, others were as close to *verbatim* reproductions of conversations as my shorthand would permit. These notes were often brief and rarely consisted of full sentences, so it was necessary to reflexively rewrite them after every shift, in order not to risk losing their meaning if I returned to them much later. The field notes included brief notes, pictures, mind maps. Each note contained the time and date and place of the observation, and pseudonyms were allocated early on in the study. I recorded in a different colour my reflections and thoughts so as to make it clear which notes were descriptions and which were analysis.

Fieldwork involved *"active looking, improving memory, informal interviewing, writing detailed field notes, and perhaps most importantly, patience"* (DeWalt and DeWalt 2002, pvii). My field notes formed a record of events observed, but they were also an account of my reflections, thoughts that arose in the moment-

to-moment unfolding of each shift. Sometimes a particular event would trigger a thought of some theory or other, and I would jot this down for consultation later that day. I also scribbled pictures or diagrams when these were felt to be more illustrative than words. I used handwritten notes which were then anonymised and entered into EverNote™, a piece of software designed for organising notes through a system of notes, notebooks, tagging and ordering.

Analysis involved reading and re-reading the notes in both the original form and the typed-up version in EverNote. This proved to be a useful device in that all the field note entries were searchable by text, which enabled repeated checking of fragments. The handwritten notes were also scanned into EverNote, and this enabled me to locate sketches and margin notes alongside the core of the fieldwork. After this, I collated data in two ways.

Firstly, I identified who were to be my key participants and assigned pseudonyms. In Phase 1 this involved members of staff and patients who came to be key participants in Phase 2 and observing how their work, and their personal and professional beliefs, interfaced with the everyday care practices. Examples that supported my theory about ideologies of care, as well as examples that illustrated tensions between approaches to care, were drawn upon and the findings directed the focus of subsequent enquiry. For example, in developing the narratives regarding the ideologies of care I drew heavily on the accounts provided by Dr Roberts, Dr Basu, Dr Frank, Rebecca and Kirsty, each of whom occupied a particular ideological position in relation to what transpired to be a trigger point for conflicts in care planning. In Phase 2 I developed the case studies for these key participants. The case study approach enabled me to identify important phenomena, in this case, the experience and expression of different aspects of suffering. It also enabled an internal logic to the organisation of the field work so that the narratives of individual patients could provide context to the thesis topic, which might otherwise be at risk of being nebulous and undefinable. Finally, the case study approach provided an opportunity for tensions and exemplars of the phenomena under investigation.

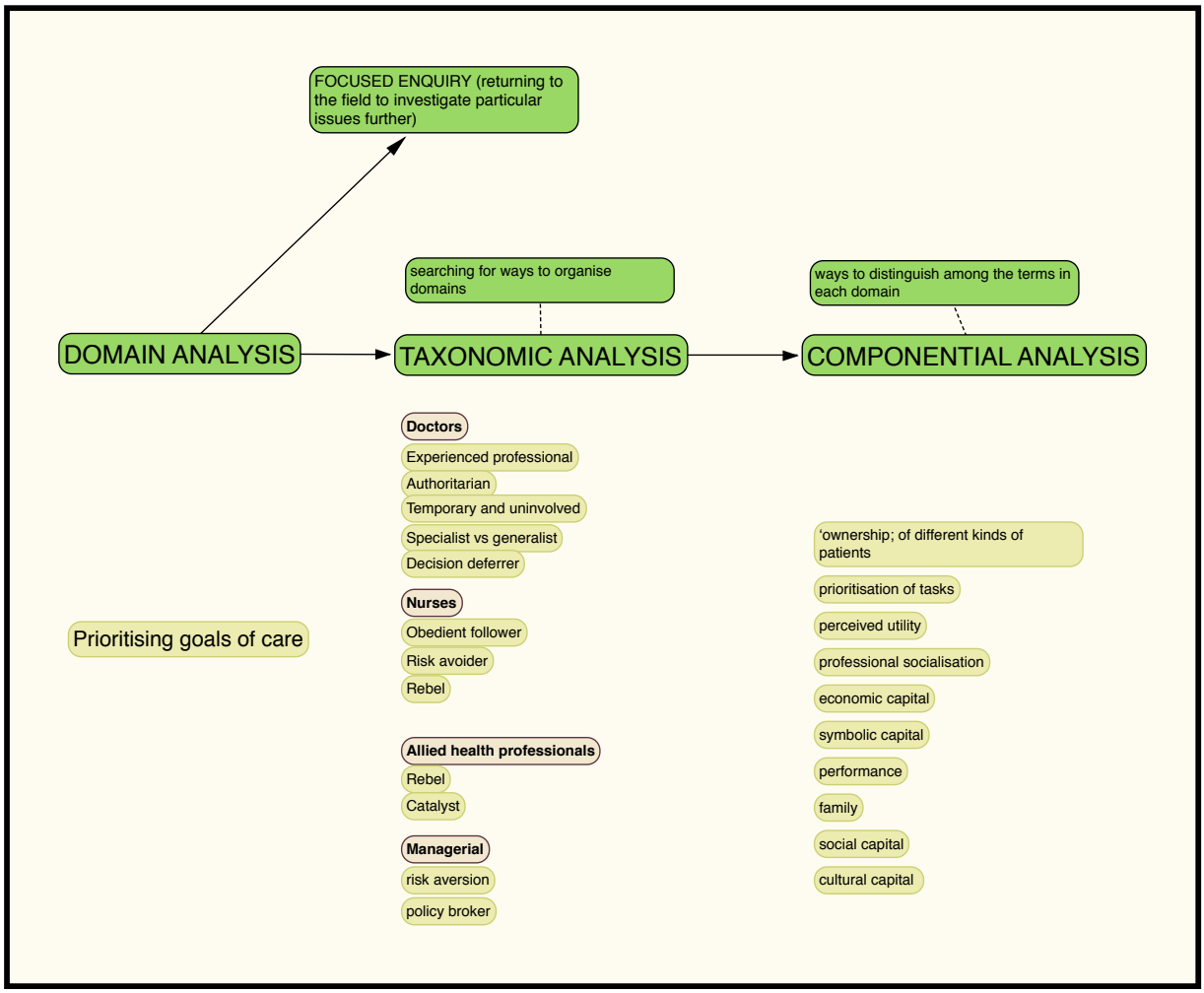
I adopted a hermeneutic approach to analysis, examining my field notes in order at the end of each day and typing them into EverNote. 'Tags' were applied as I went through as ideas arose. Some were ideas of themes, others referred to theoretical concepts that arose reflexively during the fieldwork or later, on reflection or reading. As well as reading the notes chronologically I searched according to tags, or combinations of tags. This was helpful in keeping the analysis organised and under control, as there were over 200,000 words generated over the course of the fieldwork. In relation to reconstructing the individual patient narratives, this enabled me to move from the general to the particular and then back again, and helped gain a deeper understanding not only of the lived experience of the patients but about the context of the events observed. For example, searching by 'name' tag alone would give me a set of events relating to that patient, but returning to the whole journal entry for that particular shift might shed some additional light on the atmosphere at that specific time, who was working, what other influencing forces might have been at play, other patients whose needs may have impacted on those of the one I was reading about, and so on. Tags thus formed categories and relationships, and enabled ongoing searches in different ways as the theoretical perspectives began to take shape.

Finally, notes were read with a view to looking for what was missing. The most obvious missing piece of data related to the absence of the word 'suffering' and whilst I initially perceived this to be a fault in my design of the research I soon came to understand that the absence of the word was a highly significant finding in its own right. Suffering was nobody's job. Lacunae, or missing items, can also convey a shared understanding – for example, in saying *"he'll be on a syringe driver soon"* the implications and reasons were clear. No explanation was required.

As with many ethnographic studies, there was no clear distinction between gathering and analysing data; much analysis took place during the fieldwork, and similarly, I returned to the hospital and the ward after the fieldwork to obtain further data such as photographs once the analysis was underway and I realised it would add vividity (and reduce word count!) in the findings chapters

to include pictures. Similarly, while writing the ethnography I came to realise that the process of analysis does not end. I continued to identify new themes and relationships between aspects of the fieldwork, right until the end of writing, in an ongoing hermeneutic. My approach to this was guided by Spradley's approach to ethnographic analysis (Spradley 1979) involving a series of analytic steps which move iteratively from general domain analyses to generate focused enquiry, and from the findings of this process to generate taxonomies. In turn, these taxonomies lead to further enquiries, followed finally by exploration of specific components identified during the fieldwork. The figure below illustrates a representation of the process:-

Figure 3: Spradley's analytic steps (Spradley 1979)



3.4.7 Quality

One challenge often faced by ethnographers is that of how to ensure quality in what appears at first to be a highly subjective and messy research method. In

many ways, it is both of these things, yet increasingly within qualitative research these attributes are seen as characteristics of the research rather than *de facto* disadvantages.

Authenticity

A common concern in ethnography is the issue of generalisability (Atkinson and Hammersley 1994). My focus is on a small set of case studies, yet the aim is for the findings to be of interest and utility to a wider community of practice. My hope is that the ethnography can illustrate something beyond the immediate local circumstances.

Unlike many contemporary ethnographies I did not undertake follow-up in-depth interviews. This decision was made for two main reasons.

1. Patients were generally too unwell
2. I did not believe that interview data in relation the staff's recognition of suffering would necessarily add to my research question - I imagined it would simply tell me what people thought they did in practice, and perhaps add to an already well-established body of literature relating to staff attitudes to caring for the very ill and the dying

This heavy reliance on observational data could be seen as creating a potential vulnerability in the robustness of the study. However, researchers such as Denzin (1997) suggest that this can be mitigated to an extent by paying attention to how the existing data is presented and ensuring as far as possible a sense of verisimilitude, or vraisembalance. This means that the style of writing aims to draw the reader closely into the world of the participants and the researcher, such that the experiences can be palpably felt. As long as these accounts are inherently coherent, this can create a sense of authenticity that renders the written ethnography more credible.

Initial ideas regarding themes were discussed during academic supervision, both verbally and by sending my supervisors drafts of findings chapters which initially contained much lengthier field note extracts than were included in the final thesis. This enabled extended discussion about what was felt to be

happening in each of the scenarios or situations described. A further method of analysis involved establishing an ‘experts by experience’ group. This group of people, recruited via the University’s larger Service Users’ Forum, had initially assisted in the development of the participant documentation prior to applying for ethical approval. However, all expressed an interest to remain involved in the project to some degree, and therefore an additional mode of analysis was incorporated into the design that meant that simplified and anonymised extracts from the field notes would be brought to the group and I facilitated discussions using the prompt *“what is going on here?”.* These focus groups were video recorded with consent, and later watched and analysed as sources of data in their own right. This transpired to be less directly useful for the thesis as it largely catalysed participants to relate to events in their own lives, to reflect on their own experiences of healthcare, and to gain support from one another in relation to losses of their own. So, the group was helpful, even if the content of the focus group discussions were not used in the final analysis.

Reflexivity, already discussed in chapter 2, was a further means of enhancing authenticity.

Vividity

Glaser (1978) suggests that researchers in sociological traditions contribute most when they report on what has been observed in such a way that ‘insiders’ would recognise it, that it would ‘ring true’ to an insider reading the account. Yet for Glaser it is also key that it is written in such a fashion that an insider would not have written it. An account that is too ‘inside’ would reveal “*only that which is already known. And since insiders, especially those in stressful circumstances, do not always agree with each other on all matters, a sociological narrative must also take this disagreement into account. The sociologist’s obligation is to report honestly but according to his own light”* (p9). This principle is not unique to sociology - the same might be said of an honest ethnographic account, or psychologist’s assessment. The key to this point is that the interpretation necessarily adds something new, and that rather than being seen as a ‘threat to validity’, an anti-positivist stance consists of openly acknowledging the contribution of the analysis.

Richness

By richness, I refer to the kind of *thick description* argued for by Geertz (1973). Thick description refers to the researcher's task of both describing and interpreting observed social action (or behaviour) within its particular context. The context can be within a smaller unit (such as a couple, a family, a work environment) or within a larger unit (such as one's village, a community, or general culture)). Thick description leads to thick interpretation, which in turn leads to thick meaning of the research findings for the researchers and participants themselves, and for the report's intended readership. It is hoped that this will lead readers to a sense of being able to cognitively and emotively place themselves within the field and imagine the events that were described. Also involved in production of a rich account is the requirement to consider a range of perspectives that are representative of participants, and transparently reflexive throughout. It also includes drawing out contradictions, similarities and different frames of interpretation.

Denzin suggests thick description is essential if ethnographic writing is to be interpreted by a wide range of people, and without a depth of analysis it will not be a credible piece of research.

> “a thick description…does more than record what a person is doing. It goes beyond mere fact and surface appearances. It presents detail, context, emotion, and the webs of social relationships that join persons to one another. Thick description evokes emotionality and self-feelings. It inserts history into experience. It establishes the significance of an experience, or the sequence of events, for the person or persons in question. In thick description, the voices, feelings, actions and meanings of interaction individuals are heard” *(1989, p83).*

Impact

Within health and academic research, ‘impact’ often refers to the generalisabilty of research to clinical practice. However, the potential impact of ethnographies may not relate to this, but to the impact on the reader. It has been suggested that scientific research can take up to 17 years to be implemented in clinical

practice (Mooijaart *et al.* 2015). However, a powerful narrative can change practice simply through the impact of its words. Behar argues that placing one's human self in the centre of what is happening creates ethnographers that have the power to appeal to the emotional, and not just the analytical, in the reader. Behar accurately captures this in the title of her book "Anthropology That Breaks Your Heart" (2014). I would never have contemplated picking up a research paper or book relating to the experiences of Jewish Cuban immigrants had I not been directed towards her work by an anthropologist. Yet the impact of her work on me was profound; there was a vividity to her accounts, a richness and a depth, that caused me to respond on affective and not just intellectual levels. The potential impact of powerful narratives relating to end of life care can be seen in the popularity of the recent TED talk by Chief Medic at the Zen Hospice (Miller 2015) or two recent books on mortality (Gawunde 2015; Kalanithi and Verghese 2016) or the profound effect of Bernard Crettaz's work on the adoption of death cafes around the globe (Crettaz 2010).

3.5 Conclusion

In this chapter I have outlined and justified the method adopted for the study and situated the research within the broader discipline of health anthropology, incorporating a phenomenological analytical lens to enable the inclusion of first person, embodied experiences. Greater attention to the ethical aspects of practice have been considered in Appendix 2. I have described in detail the process of carrying out the ethnography, explaining how the philosophical principles established in the last chapter were translated into practical research action. The next chapters introduce the findings of the ethnography; firstly, in chapter 4 through a 'scene-setting' chapter about the ward and its environment and next, through exploring the cultures of care and practice in chapter 5.

SECTION 2: THE ETHNOGRAPHY

Chapter 4: Welcome to the Ward

4.1 Introduction

In this chapter I describe "Bluebell Ward"[8] where the majority of fieldwork took place. I describe the political context of healthcare at the time of the study. I examine the routines and cultures that characterise daily practices on Bluebell ward. This is used to build a characterisation of the cultures of care, within which I identify the performative function of certain scripts that staff adhere to in order to demonstrate to me what they perceived their roles to be. I then describe the physical environs of the hospital and ward and the sensory atmospheres that constituted the environment of care. This is used to provide the context for understanding the patient experiences described in the following chapters.

4.2 The Field

4.2.1 The Hospital

> *"Anthropologists don't study villages…they study **in** villages" (Geertz 1973, p22).*

Although the hospital was not the primary focus of this work, a description of the organisation and its physical setting provided important context within which the subsequent relational narratives could be understood. Meadowlands hospital was located in the north of Canroyd, a large former mill town in the North of the United Kingdom with a population of around 170,000 (ONS 2015). Canroyd's population was more ethnically diverse than the UK as a whole, although less so than many nearby towns and cities; 80% white British, 10% Pakistani, 5% Indian and around 2% African. This diversity was largely the consequence of clusters of ethnic minority groups in particular sub-regions. Thus, the area immediately around the hospital had a comparatively higher proportion of

[8] *All places and names have been anonymised in the written data and images*

people of Pakistani and Indian origin. There was religious diversity too, comprising Christians (65%), Muslim (10%), Sikh (2%) and a smaller number of Hindus, Buddhist and Jews) although the 2011 Census reports a higher-than-average proportion of people who did not consider themselves to have a faith or who do not state a faith (23%). In terms of health, cancer was the most common cause of death in people below 75, followed by cardiovascular disease. There were a higher-than-average number of people with diabetes and chronic respiratory conditions. Meadowlands hospital was built in the mid 1960s, a time of rapid expansion of acute healthcare provision. The publication of the Cogwheel Report around that time heralded a much-needed attempt to organise the daily work of the medical teams in hospitals which included the care of older people (HMSO 1967).

4.2.2 Political Context

At the time of the study, the National Health Service was experiencing something of a crisis. The period of fieldwork coincided with political actions including strikes by tens of thousands of junior doctors, structures were being dismantled and reshaped with unprecedented rapidity, and there were grave concerns regarding the influence of funding cuts on the quality of care. This was perhaps most notably illustrated when a national leading institute, the Addenbrooke's Hospital in Cambridge, failed an inspection by the Care Quality Commission (CQC), the national independent regulator for quality in health and social care setting, for – among other things – unsafe staffing levels (CQC 2015). Canroyd Trust, the location for this study, was among several in the UK in serious financial difficulties. This had catalysed concern and unrest among staff at all levels about job losses and department closures.

The role of the CQC was to measure care providers against sixteen essential standards (Care Quality Commission 2010) and the inspection of Canroyd incorporated the views of 18 service users, 16 relatives and 45 staff members. The report from the previous year included verbatim quotations from patients, including *"they do so well considering the amount of staff they have"* and *"they cannot do enough for me".* Measures of dignity included that people were

appropriately covered and that curtains were drawn around them for procedures. Measures of patient-centred care included call bells being within people's reach. Evidence of people's 'inclusion and involvement in their care and treatment' was recorded as follows: *"in one person's records we saw that they had declined pain relief and this was recorded within their records".* The two other examples also related to decisions about analgesia. One piece of negative feedback from a patient was recorded as *"I feel like I am being a burden when I want to ask something and when I do they always say they will come back and they never do".*

The inspection report was positive about the use of the "butterfly" scheme (www.butterflyscheme.org.uk) and the use of the butterfly symbols to identify patients with a diagnosis of dementia on the ward, pointing out that this enabled staff to provide appropriate care planning. Practices identified by the CQC as positive were not necessarily perceived as such by staff. For example, the Butterfly Scheme cited above was never observed in use during the whole period of observation. The Butterfly magnets remained on the lower left corner of the magnetic patient whiteboard and were not moved to identify those patients requiring individualised care. I asked a nurse why these were not in use, and she replied that she never used the Butterfly documentation because she had never been "trained". Another told me that *"the butterfly scheme don't make the slightest bit of difference. There's documents in there [points at drawer in documentation cabinet]"*. I asked her what the documentation was for. She replied, *"I think it's like - be a bit more understanding, like taking into account their history, what they like, and whatnot."* Whilst seemingly emblematic of compassionate care, this lack of implementation of a scheme illustrates an example of some of the concerns introduced in chapter 1 regarding monitoring of compassion. A scheme may have been visible and apparently in use, but was not translated into practice or considered useful by staff.

A further, more recent unannounced CQC inspection had taken place a few months before the fieldwork began, following identification at an inspection the previous year that aspects of the hospital's built environment were inadequate. Certain areas of the hospital had been found to be 'requiring improvement',

particularly in relation to safety and suitability of premises. The follow-up report had been published just three months prior to the commencement of the fieldwork, and reverberations from its findings were still evident.

"It's all around the safety"

Safety was one of the key issues raised in the Francis Report, mentioned 122 times just in the Executive Summary alone. In contrast, compassion was mentioned 16 times. Given this, it is perhaps understandable that those members of staff with managerial and strategic responsibilities, who had been tasked with implementing the recommendations of the report, largely interpreted it in these terms. The culture of ongoing monitoring included prioritising completion of tasks that related to areas identified as 'high risk' – falls assessments, pressure sores, infections and delayed discharges. Documentation of these measures took precedence over documentation of care that is not mandated. Further, some aspects of care did not get documented at all. Numerous studies describe how nurses perceive documentation as being at least as important as the work itself (Tinney 2008) being the only evidence that the work has been carried out. It was often cited, mantra-like, on the ward - *"if it's not written, it wasn't done"*. Yet in his ethnographic study, Diamond (2006) describes the phenomenon of care tasks that cannot be documented and therefore do not "exist," and highlights the stress this imposes on staff who recognise residents' emotional needs. Comforting a terrified resident at 5:00 am *"was just another physically and emotionally draining moment of non-work"*— non-work because the work still got done but was just not named or paid.

The focus of policy on safety was reflected in the concerns of Liz, the Matron, when asked what she thought were the main implications of the Francis Report for compassionate care. Her reply demonstrated that despite the rhetoric of compassion in the responses to the Francis Report, the main thrust of the 290 recommendations was focused not on compassionate care but upon safety, risk-avoidance and efficiency:

> *"We really need to aim for these 11am discharges, it's all around*

the safety. If we don't push to get patients home or in the discharge lounge it has a knock-on effect. There are patients in A&E who are at the beginning of their journey, if it gets later there are fewer staff on a late to sort out the discharge, they sometimes think if they keep a bed full its less work for them to do … for example on Sunday I looked at the reports and they opened up ward 9 which is the extra capacity ward they highlighted medically stable patients to move there. Because you see we also have to meet ambulance targets. We need to have a 15-minute turnaround because otherwise the ambulances don't get back out on the road and they are more likely not to meet their 9 minute targets so if we exceed 15 minutes to get a patient transferred from the ambulance then we get fined."

Patients could be 'slept out' if a bed was required on Bluebell Ward, which meant that - as long as they were medically stable - they could be moved to any other ward in the hospital to create space. It was not just patients who could be moved. Staff could be called to work a shift on another ward if there was a staff shortage somewhere else in the hospital. Both of these practices were generally negatively perceived by nursing and medical staff but for Liz, the Matron, and Alice, the hospital's Clinical Site Commander, these were seen as an essential component of patient safety and avoiding risk, although the latter was often framed in terms of financial penalty rather than absolute risk. Even though it felt as though the ward was a 'tight little island' (Coser 1962), it was clear that the broader machinations of the hospital and in particular the focus upon safety could dictate and change ward activity at short notice.

Another common practice to maintain safety across the hospital was to move nurses from one ward to another to meet shortfalls in staffing or deal with particular pressures. The following extract is from a conversation with a senior nurse about it, a few minutes after one of 'her nurses' was extracted from the ward to go and 'fill in' on a surgical ward:

"It's sickening really. I can see it from both sides but if they move

someone they need to do an incident form, but nothing ever happens. Then if something happens on our ward because we are lower on staff we have to do a root cause analysis and if someone was moved that would be a contributing factor, but again, nothing ever gets joined up. We ended up having to change our workload model because of it. We used to have 4 and 3 on an early and 3 and 3 on a night but they'd always take someone; they don't realise how complex it is here." ["They" refers to the Site Commanders, who oversee staffing levels across the hospital].

Nursing staff were unanimously opposed to this practice for two reasons: Firstly, the ward was often perceived (by management) as being relatively well resourced compared to other wards in the hospital, but staff perceived this to be a disadvantage as they felt it led to them being readily deployed elsewhere, often to areas where the clinical work was unfamiliar and they felt out of their comfort zones. Further, they thought that the perception that Bluebell Ward was well staffed reflected a broader perception that care of older people is not complex; a misconception that they were frequently at pain to clarify, and which has been reflected in recent calls for recognition of older people's care (Cornwell 2012).

Nursing handover was one of the most important events of the day in dictating what will happen to each patient during that shift in terms of clinical interventions. Pam explained to me that its main purpose was safety: *"just to communicate who's for a call*[9]*, who needs doubles or hoisting and things"*. A range of plastic tags adorned the pod walls (Fig. 4) to be attached above each patient's bed to convey the most essential aspects of care in relation to safety.

[9] This term is used colloquially on the ward to refer to those who are or are not for resuscitation in the event of a cardiopulmonary arrest. The 'call' refers to the ringing the crash team to implement advanced life support once chest compressions are commenced

Figure 4: "It's all about the safety"

Patient 'Flow'

'Discharge meetings' were held daily in the 'Patient Flow' office in the main hospital corridor. This is where the larger pressures on the hospital became apparent. Each ward had a discharge coordinator and these were expected to update the 'virtual hospital' - a series of whiteboards along a wall with the bed numbers listed, and the gender of the occupant. Here, the Visual Hospital Symbols observed on the ward board were replicated, to give an overview of patient flow throughout the hospital. Bluebell Ward had a high number of green crosses, the symbol for delayed discharge. It was overseen by the appropriately titled 'Lead Clinical Site Commander', Alice. There was a computer screen showing activity in A&E.

> *"This is where it all begins really", Alice explains. "The greens are for patients within breach times, amber for those about to breach, and red for breaches, we haven't got any at the moment." So, we have an overview of all ward activity - patients*

who are on cardiac monitoring are a bit different, because as soon as they have their monitors taken off they have an 8-hour target for moving on before they breach. The targets on the ward are for one discharge per day before 11am". The "bed" meeting includes a video-link with the sister hospital in the Trust. She explains: "so if one hospital has some spaces we can transfer patients between sites". It is clearly quite a feat of coordination. She summarises the hospital activity: "We have had 74 through since midnight, no breaches, 16 are in department, those referred have a plan and a bed waiting. There are ten "queries" in medicine but I am not optimistic... [I later find out that this means 10 potential discharges, but she tells me these are frequently held up by a range of things - unexpected deteriorations, blood results, social issues, problems getting care packages] …If my other queries firm up I might be able to pull through the others"

Alice enjoyed talking about her role; she liked the challenge, the buzz. She felt that Patient Flow was often misunderstood by hospital staff:

"they think we just walk around hauling staff from one ward to another and sticking our noses in; they don't see that we read the notes, assess patients…wards are so busy, the staff can't see the wood for the trees…the knives I have to take out of my back every night. You have to be very Teflon-coated"

4.2.3 Ward Environment

"Human bodies are placed into situations that produce affective capacities and situations that entail new times, new spaces, and new modes of embodiment" (Wolf-Meyer and Taussig 2010)

The physical environment of the space was understood to include architectural features (more permanent characteristics of the environment such as spatial layout of hospital, room size and window placement), interior design features (less permanent features such as furnishings, colour and artwork) and ambient features (lighting noise level, odours and temperature).

Bluebell ward was one of two ‘care of the elderly’ wards at the hospital. The vast majority of fieldwork occurred here, although my research also took me to other parts of the hospital, including the ‘patient flow’ office, the café, the corridors and grounds. Access to the ward was through an intercom; nurses could see visitors through a camera and enable access. Once on the ward, the door closed and locked automatically behind. To exit required a nurse to release the lock. As a nurse, I was relatively familiar with these kinds of arrangements, but having been away from wards for some time I found myself somewhat resensitised to the subtle sense of incarceration. Once in, you were in.

Figure 5: The corridor

The door opened on to a long corridor, comprising three nursing ‘pods’. Each of these had a floor to ceiling cupboard for patient notes and ward documentation, a computer, and a telephone. Three times a day, nursing handover took place at

the pods, and they were also the locus of activity at the start of the medical ward round. The pod surfaces were often home to at least one half-drunk cold cup of coffee and a handful of chocolates, a pile of sets of patient medical notes, and a variety of forms and documents.

The corridor was bare. Fittings lined the edges but there was a clear thoroughfare for the passage of the many wheeled objects that trundled up and down its length – a whole host of trolleys: for meals, patient notes, phlebotomy equipment to remove blood, commodes, drinks, wheelchairs, hoists. The corridor was visually confusing; it was difficult to work out how long it is. Sound seemed to funnel and distort, voices appeared to belong to nobody and everybody at once. There were posters on the walls, mounted at regular intervals, that read ‘It’s Your Health: We Are Never Too Busy to Put Your Mind at Rest’. Looking down the corridor gave a first impression that there were people everywhere. Sitting halfway down the corridor and looking across, the large spaces between people became clearer. It was a strange illusory effect that the angle at which it is being observed produced a different sense of pace and activity. Sitting in one of the side rooms looking out through the small glass window in the door, it was possible not to see another human for several minutes, giving a further illusion of relative solitude despite the noise.

Side rooms were laid out in such a way as to enable the nurses to see the patient easily, through the glass panel on the door, without entering the room. This meant that all the beds in the single rooms faced away from the windows. Patients with infections were in side-rooms, to which the doors remained closed other than to allow access for members of the team or visitors. The windows did not open. These patients did not leave their room at all, other than to go home or to attend investigative procedures. Patients in side rooms had more of their own space than those in a bay, who only have curtains separating them from other patients. However, the boundaries of the side room could be transgressed at will by health professionals. Many knocked before entering but this was a formality; no patient would have declined to permit entry so in effect the knock was a signal of an imminent visitor rather than a request for access. When health professionals were in the room, they usually closed the door behind them, re-creating the patient’s room as a bounded space.

Spaces and Places

Ingold (2011) proposes that it is insufficient to merely consider the architectural and fixed aspects of the field. Indeed, the way in which the people occupy and experience spaces is crucial, and it is constituted through this activity. He contends that it is the movement within and through the space that provides the meaning. In this next section I describe the way that the spaces were embodied and the ways in which actors used them. Like Ingold, I have adopted the term 'emplacement' drawing on Merleau-Ponty's assertion that the body is not simply *"a collection of adjacent organs but a synergic system, all of the functions of which are exercised and linked together in the general action of being in the world"* (Merleau-Ponty 1962, p234)(Merleau-Ponty 1962). Pink (2011) suggests that we come to know those spaces we occupy by virtue of how we are within them. Through this means, space is understood to be equivalent to an event, that is constituted through lived bodies and we understand the immediacy of perception in relation to space, as well as the nature of our engagement by means of the senses with the material and social environment.

4.2.4 Ward Routine

When the early nursing shift arrived at 07:00am most patients were asleep. Those who were awake were being washed and dressed in preparation for breakfast by the healthcare support workers still here from the night shift. A gradual increase in noise and busyness accompanied the next couple of hours, until by the time the doctors arrive there was a cacophony of rattling cups and cutlery being cleared away. The patients were mostly awake and the phones were ringing. The morning drug round commenced at around 07:00am, and generally took over an hour. Most patients were taking large numbers of medications - as is relatively common for older people - and drug rounds were often complex.

At roughly 9:00 am each morning the medical round took place. There was one permanent consultant and one locum at the time of the study. Although patients' names on the whiteboard were associated with the initials of one or other of

these consultants, in reality they did not always get reviewed by ‘their’ doctor - this was dependent on other factors such as the numbers and locations of ‘sleep-out’ patients. The consultants were accompanied on their ward round by up to three registrars who generally arrived on the ward around half an hour before the consultants in order to get the patients’ notes correctly stacked in the wheeled trolley that they took with them. Consultants were rarely accompanied by nurses on their rounds; the time of the ward round coincided with the busiest time of the morning in terms of patients requiring washes and food. If something specific was required the doctors would notify a nurse. Shortly after the medical round commenced, a number of other members of staff appeared - this included allied health professionals, social workers, phlebotomists, pharmacists. The mornings were very busy, activity being constituted by the tasks that had to be conducted. Nurses took on a coordinating role during this time,

There were two separate times when friends and family could visit. The ward operated ‘Protected Mealtimes’ which meant that these times fell outside of mealtimes. Generally, when visitors were on the ward there was not much clinical activity. Medical reviews (unless urgent) and consultations by other professionals took place outside these times.

Night times had was a different pace and feel. Unless there was an emergency or new admission, the nurses and healthcare assistants were largely in control of the routine and they each chose to undertake the nights’ tasks slightly differently. Cheryl, who worked mostly nights, informed me that this pace changed when early morning arrives:

> *“and then when it’s about 5:00am or so you weigh up how many wet ones you have …but that’s tricky because they have a sleep policy”.*

This rationalisation of routine was often observed, a ‘weighing up’ of the different pressures on staff. It is an example of a felt tension between policy and practice; staff felt obliged to ‘start cares’ early to save the day nurses from having to do too much, too fast, in the narrow slice of time between

commencing a shift and the arrival of the doctors for the medical round. But this needed to be balanced against the 'sleep policy' which prohibited the waking of patients for the needs of staff rather than patients. Interestingly, this nurse did not describe that the tension is founded upon balancing the needs of patients and staff, but instead describes it is a tension between two sets of rules – that of helping out the early shift nurses, and that of adhering to policy. Such constitutive rules were shared, and create a sense in which behaviour of nursing staff was shaped in predictable ways, whether on a night or a day shift. This tension highlights the interface between the governance of the hospital, nurses' personal interpretations of practice, and the meaning systems and behaviours that arise through the interpretation of the governance structures.

Most nursing and support staff preferred weekends to weekdays. They valued the space offered by the weekend:

> *Domestic assistant (leaning on mop) "Floors are easier to clear because there are fewer people in the way"*
>
> *Becky (nurse) (nods): "There are no doctors' rounds, no physio and dieticians, social workers and OTs…we have more time to spend with patients, we don't have to worry about finishing washes before the doctors arrive".*

This view was not shared by all. Rachel hated them - *"they're so slow. Sunday lates, I often just find myself thinking - I could be at home".* She was more attracted by shifts that were exciting and fast paced, even though she admitted that these exhausted her. At the time of the study, however, there were external pressure to increase medical cover and core hospital activity at the weekend. Jeremy Hunt, the Health Secretary, had responded to a piece of research identifying increased mortality at weekends compared to during the week, made a promise to increase weekend working in acute hospitals in the NHS. There were claims that Hunt had misused the research by claiming such causal links, and the medical professional were at pains to point out that they were already working excessively long hours (Oliver 2016). A Twitter campaign gained

momentum, with over ten thousand NHS staff responding to the #ImInWorkJeremy hashtag.

Staffing was a constant source of discussion and complaint among the nursing staff. In particular they were ambivalent about the use of agency staff who they perceived to be paid more money than them to take on less responsibility. Pam told me about a Bank Holiday when an agency staff nurse had worked alongside her on a 14-hour shift for almost double her pay, but was unable to administer intravenous antibiotics, set up enteral feed pumps, or reprise syringe pumps, so all three of these tasks had fallen upon her.

Readily available data related to the hospital staffing levels, or 'Fill Rates[10]' for the month of the study illustrates that registered nursing staffing during day shifts was at 94.3% of recommended level for qualified nursing staff, and 87% for healthcare support workers. Night shifts showed a different pattern, with registered nurses being at 75.3% of recommended levels, but healthcare support workers being over-utilised at 118.3%. This practice, I was told, is common in the hospital where wards have been advised to cut costs. The numbers of nursing staff on the floor was unchanged, but they were comprised of a different skill mix to that which is recommended. This reflected a further concern of nursing staff, which related to the perception that Older Peoples Medicine (OPM) was a relatively unskilled and heavy area to work in. This had two consequences; firstly, they considered that from the perspective of management, it meant a healthcare support worker was not viewed as any different to a qualified nurse in terms of their role. From another perspective, staff felt that wider views of OPM as an unattractive clinical area in which to work were reinforced.

The ward was a busy and challenging place to work although staff differed in how tolerant they were of the level of busyness and the nature of the work. There were ongoing tensions in relation to pressures on (and from) the wider hospital, as personified in the input from the Matron and the Clinical Site

[10] 'Fill Rates' are a business term that refers to the percentage of customer or consumption orders satisfied from stock at hand. It is a measure of ability to meet demand.

Commander. The apparent rigidity of the physical environment and the routine served to convey to staff and patients a sense of order and safety.

Going Home

> *We leave his room. "He thinks he's going home", I say to Kirsty.*
>
> *"They all think they're going home", she replies.*

The ethos on the ward was to commence discharge planning from the moment a patient was admitted to the ward. Coloured magnetic symbols were placed next to the patients' names on the whiteboard in the corridor. Sue (the Discharge Coordinator) began her day by going through her 'green crosses'. These were the patients who for social or functional reasons were unable to leave the ward, although they have no clinical reason to be there. Sometimes this was because they can no longer be at home but there were disagreements as to how to fund placements in care homes, typically between social and health care as these were different funding streams with different mechanisms. The ritual for discharging patients was complex.

To try and make it comprehensible to all staff it had been formalised as a tick-list, although usually the order of things was not linear. 'Patient medically predictable' was the first criterion to be met, whereupon three further criteria were required. The italicised reasons were what I was told by staff when I asked what the rationale was for each criterion:

1. Medical stability *(avoiding readmission)*
2. Mental capacity *(avoiding incidents)* or family happy *(avoiding litigation)*
3. Mobilising safely *(avoiding litigation)*

Medically stable patients would often become medically unstable again, at which point the 'Section 2' referral to Social Workers would be revoked and the process would begin again. The order of events was often variable dependent on staff and patient factors, such as the relationship between different professionals.

4.2.5 The Sensory Ward

In this section I describe Bluebell Ward by drawing on the principles of sensory ethnography outlined by Pink (2015). The ward was a sensorium; being there was an embodied experience. I describe different sensory aspects of the ward in turn, attending to *vision*, *hearing*, *touch*, *smell* and *taste*. I have also added *places and spaces, movement* and *time*. Even though these were not strictly bodily senses, they are components of what Pink calls 'emplacement' - which can be summarised as attending to the experience by accounting for the *"relationship between bodies, minds, and the materiality and sensoriality of the environment"* (p11).

Engaging the senses other than sight because easier over time, but felt far from natural at the start of the study. Particularly those senses other than sight required a process of internally blocking out one sense or another until over time it became a more natural skill. For example, I spent a day just studying noise and sound from different vantage points (inside a patient's side room, the nurses' station, the staff room, the kitchen, the corridor). Distinguishing individual sounds was challenging, as was separating out the sound from trying to visually locate its source. To facilitate attention on to those senses less used, I spent some time with my eyes closed (to the amusement of staff). The following extract is an example of how multisensory data was recorded in the field notes:

> *Macerator in the dirty utility room chews up cardboard commode pans & effluent contents and flushes them away, opening like magic to reveal a still-gleaming yaw. Trolley wheels rattle - the newsagent trolley w/ papers, chocolate, drinks and sweets. Smell in V's room – is it old tobacco, stale urine, illness? - can't quite capture the nature of the latter. His breath, I think, and an acrid smell that comes from his skin. Slippers frayed and worn, slightly damp and cold to touch. I take them off his feet: the smell hits the back of my throat.*

Light

The corridor had no direct daylight; it was flanked by single rooms and bays, all of which had at least one window. These could not be opened, for safety reasons, so although there was a view of the sky and surrounding town it was a purely visual experience. The sky may have been blue, but once you were inside the ward there was no telling whether it was a warm and balmy day, or a crisp autumnal one, or whether the cooking scents from the nearby pub drifted this far downwind. All patients had a view of a window, although for those in bed (the majority of patients) the view was of the sky alone as the windows were too high to afford a view. Several of the beds faced away from the windows. Usually these belonged to patients in side rooms who needed to be observed by nurses, via the small windows in the doors. These patients had few choices about what to look at. They could lie back and look at the ceilings; grids of light and white tiles, or they could look at the window but generally the beds were placed too low to be able to see the view, and the blinds were frequently closed: **(Fig 6 and 7).**

Figure 6: View from a bed (1)

Figure 7: View from a bed (2)

There were three main sources of light. Fluorescent strip lights and bright spots in the rooms illuminated staff activities. Overhead lamps by patient beds were available but rarely switched on; the light these emitted was a warmer colour than that from the overhead lights, but given that the latter were almost always on they were rarely used. If a patient was awake at night, they would be encouraged to switch off their light and go to sleep, or if they needed to be seen by the nurse it would usually be by torchlight to minimise disturbance of other patients. Even with all the lights in the bays and side rooms switched off at

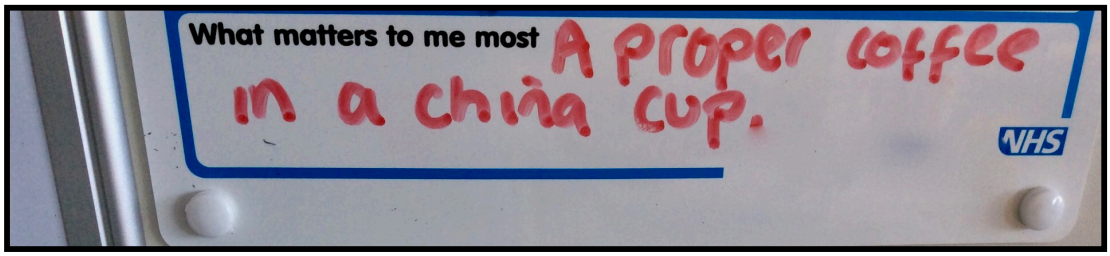
night, there was still a spilling over of light from the corridor, through small windows and under doors. Nowhere on the ward was truly dark at night.

The corridor floor was highly polished, reflecting objects and light. Research suggests that this can cause glare which can be disorientating for older or visually impaired people (Dalke *et al.* 2004). Most of the other surfaces on the ward were highly reflective too; furniture had a sheen to it; a consequence of being manufactured from materials that were easily washed and wiped clean in accordance to infection control procedures. The overall impression was that everything is somewhat hard and plastic, with the exception of the bed sheets and pale blue waffle-weave blankets.

Objects

The 'personalised patient care' whiteboard behind one patient's bed contained a section called "What matters to me most". Most of these were left empty, but occasionally they were completed (as in **Figure 8** below). These boards were rarely completed if the person had difficulties communicating.

Figure 8: What's important to me



Most patients wore standard issue hospital gowns, drank from plastic cups or feeders, and a small collection of cards or flowers were clustered on bedside lockers alongside sputum bowls, mouth care swabs or other hospital paraphernalia. It was rare to find objects of sentimental or personal value in patients' possession. Further, there were few objects that belied individual identity; objects belonging to patients usually had some kind of utility - for example, alleviating boredom, as shown in **Fig 9** below:

Figure 9: Objects of occupation

As well as ‘occupational’ objects, patient’s spaces often had the kinds of paraphernalia associated with visitors coming to see a sick friend or relatives; bowls of fruit, flowers, cards. In one extreme case, a patient (‘Dot’, who will be discussed in greater detail in Chapters 5 and 7) was moved to a side room because she was thought to be in the last weeks of her life. Over a period of a few days and numerous visitors the room gradually filled with helium balloons attached to plants, bouquets of flowers, hand-drawn cards tacked to the walls, drawings by her many grandchildren. Although she wasn’t eating, her locker was piled high with her favourite foods. If a nurse needed to access the medicines locker by the bed, it was first necessary to negotiate a range of physical obstacles - in the form of things and visitors. She was never alone. This was not popular with the nurses - they found it frustrating to have to “do cares” because they first had to clear the room of visitors. They also expressed concern that it might be oppressive for Dot to be surrounded by so much hubbub. Staff had to prioritise access to patients, equipment and the patient-specific drugs lockers over the lesser need to create a homely space; and when the latter was taken into the hands of families, there was frequent resistance from the nursing staff on the grounds of access and infection control.

Outside the Day Room the walls were covered in paper chains, posters - both handmade and printed - to raise awareness of dementia and person-centred care, and a rack of leaflets about living with dementia **(Figure 10).** This space was an area of high traffic. Located in the centre of the ward where the corridor widened out to enable a range of activities, lunch trolleys were temporarily parked while the trays were removed and distributed, groups of staff congregated on their ways in and out of the various rooms flanking the space (Day Room, Clean Utility, Sluice, Kitchen), and patients who were able to mobilise were drawn here - often sitting on the row of chairs opposite the wall where this was displayed. When sitting on this row, it was not possible to discern any of the content of the posters on the opposite wall. Instead the impression was of 'visual noise'. The somewhat more restful image behind the seats was only visible when walking past; there was no seated vantage point from which to look at it. It has been suggested that 'visual noise' can be disconcerting to older or visually impaired patients (Dalke *et al* 2004).

Figure 10: View from the seats

Sound and Noise

> "I wanted, I thought, only a little,
> two teaspoons of silence"
> (Hirshfield, 2015, p63)

From the moment I entered the ward I became immersed in a soundscape that was characterised by continuous sounds. Even during the night, when it was relatively quiet, the hiss of alternating pressure mattresses, the low-pitched hum of the oxygen piping and intravenous infusion pumps was superimposed on to other sounds. Some of these sounds were sporadic – a patient calling out, muttering, footsteps, the clatter of the nurse checking the medication stock in the trolley. By morning the volume and complexity of the sound increased. When the morning nurses arrived for 07:00am there were buzzers beeping, trolleyed commodes being wheeled in and out of rooms with squeaks and rumbles, running taps, flushing toilets, and the metallic clanks of hospital bed cot sides being raised and lowered. During nursing handover, there were three small clusters of nurses and healthcare assistants a low murmur of voices as they plan and allocate tasks, overlaid with calls from the healthcare workers: "*Bed 4's ready for a shave"*. Cheryl, the night nurse was trying to hand over *"her little lot"*. She grinned at me, said *"I can't bloody hear myself think here"* and returned to the crumpled sheet of paper from which she reads important events relating to each patient. Some patients banged objects to try and attract attention; spoons on tables, mugs against metal cot sides. Foot pedal controlled bin lids squeaked open and clanked closed, plastic aprons rustled as they were opened up, tied on, then torn off and crumpled up. There were calls and cries, and the patient call bells emitted their intermittent sharp beeping almost continuously. An intravenous infusion, having delivered the required volume of fluid, gave a different type of beep; higher pitched, quieter. In the sluice, the macerator growled as it is fed cardboard bedpans and their content. Some patients, identified as being at risk of pressure damage to their skin - especially those who were bed bound or particularly underweight or overweight - had alternating pressure mattresses. These created a sporadic hissing sound as the

cells under the plastic mattress filled with air and then emptied, accompanied by the low hum of the motor that controls this process. Other, more mobile patients considered to be at risk of falling had clips attached to their gowns. If they ventured beyond a certain distance from the wall by their bed, the clip pulled a magnetic cord which set off an alarm to alert the nurse that the patient is moving. Sometimes these alarms were pre-recorded with a message: *"Horace, get back into bed please"*. These disembodied voices could often be heard several times an hour. Other times the alarms just set off a buzzer.

Eating and Taste

I had limited access to eating together with patients, too - meals were swiftly handed out and those who required assistance were fed, generally by the healthcare support workers, but sometimes by staff nurses or student nurses. Sometimes I helped patients to eat, as in the following reflection:

> *In side room with Sheila. spooning porridge into her mouth. Dabbing her chin when some falls. Less on the spoon next time, I think to myself. I sit in silence, she chews and swallows, her eyes looking out of the window. Sometimes spits it out, sometimes seems to enjoy. I find myself mirroring her act of eating (like when my children needed feeding) licking my lips, saying "mm", and swallowing when she did. Occasionally a baffled expression would move across her face and she would stare, first at her food, then at me. I came to learn that this was a sign of impending anxiety. During these times, she might throw her food across the room, reach out to slap my hand, shout out "no!". Eating takes as long as it takes.*

Olfactory

The following excerpt illustrates how the particular combinations of odours on the ward had become normalised for staff who work with them daily:

Walking with Eve, a healthcare support worker. She wheels a commode - cardboard bedpan of malaena - faeces, mucous and blood to the sluice. She deftly opens the lid of the macerator, dumps the bedpan inside, and closes it as it emits a grinding noise. The contents are pulverised and disappear into the waste pipe. She washes her hands, pumps a couple of squirts of alcohol hand rub on to her hands. Then she says, "I'm starving" and we go to the kitchen. She takes a plastic container of pasta bolognaise from the fridge and puts it into the microwave. I ask her how she manages to keep her appetite, to move so swiftly from excrement to food. "Oh, you just get used to it", she tells me.

I recognised this. As a nurse, I would have thought nothing of doing what she just did. Several years out of clinical practice and I noticed that my sensitivity to the aversive experience of disgust had returned. The kind of body work that nurses and healthcare support workers undertook required that they were able to manage the habituated responses to the smells of deteriorating human bodies. *"Cadaverous, sick, disabled bodies…are all part of nursing work"* (Holmes *et al* 2006, p305).

Stoller, when describing his ethnographic research in Niger, Africa, described how his initial experience of the field was an assault on his senses. Over time he found that his sensory vulnerability was diminished:

"I quickly lost touch with those scenes of abject deprivation which blended into those of insensitive consumption. I soon lost scent of the nose-crinkling stench of the open sewer that gave way to the aromatic aromas of roasting meat. My ears soon deafened to the moans of a sick child that were overwhelmed by the happy laughter of a healthy one. I had become an experience-hardened Africa hand. My immersion in Niger, in Africa, had been, in short, distanced, intellectualised - taken out of the realm of sensual sentiment. The world of ethnographic things had lost its tastes." (Stoller 1989, p20)

Abjection, or distancing, is one way in which it is thought that nurses manage disgust (Lawler 2006). If abjection was important in order for nurses to engage in body work, and this is - as argued by Menzies Lyth - a means of self-regulation, then it also has implications for the broader understanding of compassionate care.

I argued in chapter 2 that one cannot study suffering without analysing the impact of intersubjectivity. I also suggested that this process requires embodied awareness. The same is true of the kind of body work carried out by nursing staff; it is through the body that many subtle aspects of relationship are identified. It might be suggested that the process of abjection led to a state of disembodied nursing, a distancing that could have adversely impacted upon sensitivity to the embodied aspects of suffering. Losing one's dignity emerged as an important aspect of participants' suffering. If nurses had become desensitised to bodily functions and processes then they may have also inadvertently have lost sensitivity to how this might be perceived as an affront to dignity. Edvardsson and Street (2007) suggest that the process of socialisation into nursing often involves 'tuning out' aspects of sensory experience that are associated with the bodily elements of nursing practice, that which Lawler termed *"somology"* (Lawler 2006). They suggest that this desensitisation may be a reason that much of nursing observational research is surprisingly disembodied, a view echoed by (Gadow 2001, p90) who suggests that disembodied nursing philosophising is akin to *"trying to persuade us through argument that there is more to life than reason".*

Motion

Many kinds of walk were observed. Nurses tended to walk rapidly, purposefully, with the exception of a relatively new nurse and the student nurse. The rapidity of the walk seems aligned with the imperative to get things done efficiently and rapidly. One morning Kirsty walked from the patient bay towards the pod to hand over the patients she had been caring for that shift, she theatrically dragged her feet, with a pained expression. I asked her if she was alright.

"I'm so tired today. When I woke up I didn't lift my feet high enough walking over the threshold of my bathroom. Cut my foot. I'm on autopilot today, feel like I'm running around without direction"

Doctors' walks were different again. They moved purposefully between patients, pushing the wheeled trolley of patient notes from one room to the next. The consultant would lead, and two or three junior doctors would follow. They parked the trolley outside the door, then went in - the consultant first. The junior doctors hung back and listened. Once the consultation was over, they regrouped as a huddle around the trolley to discuss their findings, differential diagnoses, investigations to be planned, clinical conundrums, leafing through the file. On the consultant's say so, usually indicated by a change of tone of voice and closing of the patient's notes, the huddle moved on to the next patient.

At times the different staff walks clashed. Medical rounds generally started at around 09:00am, and often the patients were still finishing breakfast, having washes, using the toilet. On one occasion, the notes trolley was parked in the entrance to a bay, and Edith moved to push it aside so she could fit the commode past; she was taking it, somewhat hurriedly, to a patient who had been calling out to use the toilet. The consultant told her to wait, that he is in the middle of his medical round. She flushed and coloured, and retreated.

For patients, walking was generally disapproved of, unless in the safe contained space of an encounter with a physiotherapist or rehabilitation assistance, where the prudent use of a range of devices (banana boards, walking frames, wheeled zimmers) enabled walking to take place safely. Cheryl believed that patients were often prevented from walking by staff because of a perception that it was easier and safer, but expressed concern that this led to a loss of independence, as well as tension when patients were required to navigate different staff expectations: *"then the patients expect to be helped and when I'm telling them to walk they say, 'well that other nurse, she gives me a bedpan…"*. It was challenging when patients' levels of mobility were variable: *"like him, when you*

stand him he can't take his weight but I found him down the corridor with a visitor's chair the other day".

Figure 11: Walking a mile in their shoes

Walking could also be seen as a proxy indicator of general health; one morning, Doris asked Dr Roberts how her general health was, and he responded *"well, I just saw you walking back from the bathroom with your zimmer, I would say that your general health is not bad walking on this floor"*. This was clearly understood. Doris beamed, adding *"well at home I've got carpeted floors",* implying that things would be even easier. Being able to walk safely is the best ticket out of the ward (along with having mental capacity, a stable medical condition, and a family who agree with the decision to discharge).

The speed of activity on the ward meant it was easy to forget to be still. Leaving the ward one day, I suddenly remembered my body:

> *first breath of fresh air since 6:30 this morning and the sun is shining and it's warm, I can see it sparkling off the windows. It might have been sunny while I was inside, but I didn't really look, it's that kind of sterile one temperature environment in there, so it*

passes you by. I haven't really had a feeling of what time of day being, and have not really been aware of hunger. I got my period and forgot about it, and forgot to do anything about it. It's a weird sort of distancing from my body and it seems like it happens to the nurses as well. They sit down on their breaks and it's kind of endlessly talking about their ailments and tiredness and backs on the ankles and things like that, so it's an effect. I think of being around bodies that are in such decrepit states that naturally forget about your own.

Temporality

In Phase 1 of this study where I was a participant observer I spent each shift following different staff, becoming acclimatised to their routine. My abiding memory of this time was of speed; there were always so many things to be done and seemingly so little time in which to do them. Staff continuously informed me - either directly or through behaviour - about how busy they were, and how there was never enough time to do the job. Those staff who were fast and efficient were talked about in admiring ways: "*she gets the job done",* and *"she is very experienced, very competent. No tasks get left over at the end of her shift".* Being motivated was more desirable than being unmotivated, being happy was more desirable than grumpy and in the following example, being fast was preferable to being slow:

At the start of a shift I greet Becky, one of the nurses, a young and energetic staff nurse. "How are you?" I ask. "Alright", she says, "Except I'm working with a bloody snail today". She rolls her eyes and grins. Her right-hand nurse is Dot. A few days earlier, Dot describes herself as a spiritual and creative person. She practices mindfulness meditation, and tells me this helps with the stresses of the job. In her spare time, Dot writes poems and paints pictures.

Dot did not fit the ideal of the efficient nurse. She took her time over seeing patients, which sometimes meant the medications get given out late, or she was unavailable to help the healthcare support workers 'finish washes' before the doctors arrived for their morning round. In her attentiveness to each individual patient, Dot made herself less popular with her nursing colleagues. She regularly broke the rules that constituted the script of efficiency. It was not only nurses who prided themselves on speed. One morning, a junior registrar proudly reported to me that he had finished the medical round in under two hours. *"18 patients"* he grinned at me.

The Clock

Patients experienced time very differently. When I entered Phase 2 of the fieldwork and began to spend time primarily with the patients I became increasingly aware of this discrepancy in the perception of time. There was a discernible change of pace. Staff rarely considered that boredom was an issue of concern for patients because as far as they were concerned, there was never enough time on a shift to get everything done. Time flew. Conversely, patients frequently perceived staff as busy and this often meant they did not ask for help as they felt they were imposing.

At first, I was restless. It seemed there was always something happening somewhere else. I could hear the bustle of the ward but it was distant and the causes of the sounds were incomprehensible. I watched the clock and each hour takes an age. I found my concentration drifting, at times I became unsure as to what I was supposed to be observing. The early days of this practice were the hardest. Sometimes I was impatient for something to happen. When someone enters the room - to empty a catheter bag, to take a temperature - I was elevated, energised. When their visit is brief and perfunctory I was resentful. I wanted to be able to observe how they interacted with patients, but often these interactions were perfunctory, functional.

It struck me that patients must feel similarly. Several patients had mentioned watching or staring at the clock. My enforced stillness gradually became a

valuable means of observing. Whilst it produced much less in the form of the voluminous field notes of the earlier days, it offered something new and different. It slowed down the field of observation, enabled me to separate out different sensory experiences, make use of imagination to feel into what it might be like to lie in these beds, sit in these chairs, and watch these clocks (Fig 12).

Kermode refers to human endeavours to impose structure upon time, which is essentially disorganised and chaotic.

> *"the clock's 'tick-tock' I take to be a model of what we call a plot, an organisation which humanises time by giving it a form; and the interval between 'tock' and 'tick' represents purely successive, disorganised time of the sort we need to humanise" (Kermode 2000, p45)*

Figure 12: Staring at the clock

4.3 Conclusion

The environment of Bluebell Ward was a ceaseless flow of stimuli. To an outsider the activities presented an impression of order and purposefulness, against a backdrop of various sensory phenomena that in aggregate conveyed coordinated activity and intentional movement. Patients often described that they were aware of how busy the staff are. Staff carried out their various activities while simultaneously prioritising and planning the remainder of what needs to be done.

In Christopher Alexander's celebrated 'Pattern Language', a series of connected patterns of design for interior and exterior spaces are presented,

placed in a context of the purpose for which the space is intended. In his vision of a pattern for complex healing environments he notes the importance of flexibility of space:

> *"in a complex, social fabric, human relations are inevitably subtle. It is essential that each person feels free to make connections or not, to move or not, to talk or not, to change the situation or not, according to his judgement. If his physical environment inhibits him and reduces his freedom of action, it will prevent him from doing the best her can to keep healing" (Alexander 1977, p628)*

Alexander observes that because hospitals depend on sickness, in a sense they also contribute to its creation. Death is a human rite. Rites of all kinds cannot take place in an environment which specifically ignores them or makes them trivial. Seen in this light, the idea of a 'care of the dying' pathway prohibited the experience of dying as a psychosocial and spiritual experience. On the one hand, such tools seek to capture and guide best practice in many of the skilled aspects of caring for a dying person – controlling distressing symptoms, communicating with the person and their family, attending to spiritual needs. On the other hand, such pathways were filed in drawers along with weight charts, fluid intake and output charts, and other highly clinical aspects of care. They were not marked out as being different or special in any way, and so were treated as any other clinical pathway might be. Sudnow's critique of dying in hospital (1966) although now almost half a century old, observed that the hospital dealt with the biological aspects of death, and many people underwent social death prior to the moment of the cessation of bodily functioning. This observation is still pertinent; there is little on a care pathway to identify this person as any different from anyone else whose biological body is dying.

The content of this chapter has served two purposes. Firstly, it has established for the reader a sense of the field of study in order to place all subsequent data in context without the need to again describe the physical environment. This 'field' has been conceptualised in sensory as well as functional terms. Secondly,

it has laid the groundwork for what will be returned to in chapter 9 when I explore the role of the environment in iatrogenic suffering. In the next chapter I examine more closely the kinds of practices involved in direct patient care in the context of end-of-life care.

Chapter 5: Rock, Paper, Scissors

5.1 Introduction

The subject matter for this chapter is the way in which professional identity and personal beliefs informed the direction of care. Care of older people was provided in a complex environment, by a dispersed multi-professional team, to patients whose illness trajectory was characterised by ambiguity and frequent changes in condition. This chapter continues the work of describing the 'field' that was begun in the previous chapter, but now focuses this on to the team and its practices. I begin by describing Bourdieu's 'logic of practice' (1990, 1992) as the theoretical lens. I continue with an overview of ward culture (comprising various subcultures), supported with selected examples from the fieldwork. I draw on the concepts of *field, habitus, doxa and capital* to explore mechanisms of power at play within and between these subcultures. Three distinct discourses were suggested, each constituting a different ideology of care where ideology was understood to refer to a system of ideas, or set of beliefs, adhered to by a group of individuals.

I term these ideologies **rescue, rehabilitation** and **release.** I describe ways in which they differ in their historical roots and clinical foci. For each ideology, I present an illustrative case study from the data, then I examine what happens when things were not quite as clear, as for example when people transitioned from 'living with' to 'dying from' a condition. I suggest that the ideologies were often closely aligned with particular professionals, and each dictated a particular direction of care. By way of illustrating how these positions interact, the example of the game 'rock, paper, scissors' has been chosen as the title for this chapter. Like in the game, decisions in practice must be made at speed and without knowing what the outcome is going to be. If I were to choose 'paper' and my opponent's choice was 'rock', I would win. However, if they were to choose 'scissors', my paper would be 'cut' and I would lose. The ideological positions stood alone; a rock has no insight into what it is like to be a piece of paper, and vice versa. Clinical situations presented uncertainty; pursuing the goal of rescue means that simultaneously considering palliative needs was difficult. However,

the relationship between ideologies was, I shall argue, not an equal one as in the game. I will demonstrate through exploring the clinical disciplines most closely associated with each ideology that there were differences in power which meant that there was usually a dominant ideology, and that this was likely to be the default position in situations of uncertainty.

The ideology of rescue - located in the clinical practice of acute medicine and regulated within the broader context of neoliberalism and healthcare bureaucracy - dominated over the other two when ethically problematic clinical decisions needed to be made in an atmosphere of uncertainty or ambiguity. I suggest that the dominance of the rescue ideology was a consequence of the unequal distribution of symbolic capital between the different professional groups who were involved in the decision-making process, and was reinforced by risk-averse practices that characterise ward and hospital culture. This could in some cases cause or exacerbate patient suffering, particularly where it resulted in inappropriate or burdensome interventions at the end of life.

5.2 Theoretical Perspectives: Bourdieu's Logic of Practice

This chapter considers the relevance of Bourdieu's theory of practice for understanding how the different clinical positions relate in the 'field' of the ward and wider hospital. Firstly, I define his main concepts that will be increasingly drawn upon as the thesis develops. For each of these, I briefly explain why this concept became useful in understanding the practices that were observed.

Pierre Bourdieu was a prolific anthropologist and sociologist who was concerned with ways in which power is sustained within societies and is a product of both individual and societal processes (Bourdieu 1977; Bourdieu and Wacquant 1992; Grenfell 2014). He rejected the traditional division between subjective and objective explanatory theories, and proposed instead a simple explanation that sought to examine the interface between the individual and the societal, particularly focusing on the ways in which power is transferred across generations. His conceptual framework posits an interaction between individual agency and structures where neither can determine lifestyles or practices. He

rejected the notion of freedom, suggesting instead that the construction of individual identity takes place within constraints presented by social legacy.

Bourdieu's philosophical position was that people's actions are neither determined by structure nor by complete freedom of choice. Instead, people are bound by a legacy of characteristics and dispositions, formed of their upbringing and social standing which collide with their objective circumstances at a given point in life. It is the combination of these events which dictate the extent of freedom one has, the degree of power to act within a particular field, and the comparative social standing with others in that field. He believed the constraining influence on freedom of choice results from a combination of *field* and *habitus,* where the former refers to the context in which the individual is seeking to act, and the latter refers to a set of dispositions that have resulted from objective conditions (Robbins 2016).

5.2.1 Habitus

Habitus refers to a system of *"durable, transposable dispositions"* that exists in relation to the objective structures that constitute the social world (Bourdieu 1977, p72). Habitus includes the thoughts, emotions and perceptions that a person acquires within their social position, which leads to people having a natural way of thinking about things that is consistent with others who share their location in the social world (Williams 1995). Importantly, habitus establishes a set of social practices that are outside normal conscious awareness; these practices have their own logic. Bourdieu describes agents as having a *"feel for the game"* (Bourdieu 1990, p61) when enacting aspects of habitus, implying an intentionality, yet one without consciousness (Bourdieu and Wacquant 1992). Bourdieu suggests that habitus is what gives an individual consistency in the ways that they act. It is perhaps best understood as a set of internalised structures that have themselves been produced by the environment in which an individual finds themselves. So, habitus is formed of the objective structures of the world, but it dictates how one acts in the world too.

Habitus is unconscious, so internalised are the patterns. It is also pre-reflective, such that an individual asked about a particular action may not be able to articulate a rationale for said action. Bourdieu suggests that for this reason it is

unhelpful for researchers to ask why a person is performing a particular action, as the action may well be a product of habitus and result from a taken-for-granted set of circumstances that defy explanation and explication. Habitus is shared, to an extent, between members of the same societal group. Although not identical, such members will have more in common with habitus of others in the group than with the habitus of people in a different group. Finally, habitus is specific to a particular field and only operates within that field. The kinds of values that are defined as normal by a particular group are operative only in one context; in another context, their accumulated set of dispositions may be very different and they may demonstrate a different degree of symbolic capital.

The reason for adopting habitus as a theoretical perspective in this thesis is as a way to understand the differences between what people did, and what they said that they did. It also provided a valuable mechanism for making sense of how various practices were reproduced over time by different agents in the field. For example, patient habitus was unlikely to be compatible with this new and unfamiliar field. They had not yet developed a 'feel for the game' or the kinds of internalised structures that give preconscious awareness of how one might need to operate in order to gain status within the field.[11]

Another example was the way in which professionals on the ward shared habitus more closely within their perceived in-group (primarily defined professionally in this context). The doctors occupied a different room on the ward during their breaks, one which could only be accessed using a key code and which housed a shelf of medical textbooks, a computer and a telephone. In this space topic of conversation were varied; talk of holidays, analysis of the comparative generosity of different consultants with regards to expectations for on-call cover. The computer in the doctors' room was never switched on. Should a doctor need to access information about a patient or disease, they would do so on the computer terminals in the nursing pods, in full view of the staff. Nursing and ancillary staff spent their break time in the 'day room' a space

[11] Note that this can change over time when patients become institutionalised; the 'feel for the game' can be learned and patients can develop the knowledge and skills to enable them to successfully navigate the field and acquire capital despite beginning from having diminished agency.

intended for use by patients and families as well as staff, but which in reality was only accessed by relatives when there were difficult conversations to be had, and as far as I could tell, never accessed by patients. It primarily functioned as a space for nursing and ancillary staff to spend their breaks. The day room had no computer. There was a small pile of glossy magazines, “Hello!”, and “Yorkshire Life”.

The differences between these groups of staff was particularly noticeable when the spatial boundaries were transgressed. Fran, a new medical registrar on the ward, arrived on a day when the regular Consultant was not working. Not knowing about the place where the doctors took their breaks, she sat herself at the table in the Day Room and took out a piece of fruit. Two nurses, sitting opposite, sipped their drinks largely in silence, sometimes exchanging pleasantries. On one level this interaction can be seen as simply the arrival of a new person in an already-established social group, and the resultant dissonance is there as mutual scrutiny. Bourdieu’s notion of symbolic capital is resonant here; symbolic capital is automatically assigned to members of a particular group. Fran, as a doctor, transported her habitus with her into this new field; her habitus, a composite of her capital, resulted in a state where she knew how to behave with the other medics despite not having met them before, but when she met the nursing and ancillary staff there was an atmosphere of uncertainty and dissonance as the staff evaluated Fran, apparently seeking to ascertain what ‘type’ of doctor she would turn out to be.

5.2.2 Doxa

Doxa refers to commonly-held beliefs and is used by Bourdieu to describe the relationship between the senses of reality that is created by habitus. Bourdieu uses the term to explain that which is taken for granted in a particular societal group; it describes what is thought by members of that group to be self-evident and require no explanation or elucidation (Bourdieu 1972, p164). Doxa is predicated upon how closely there is a connection between the field and its objective structures, and the internalised structures in a person’s habitus (Throop and Murphy 2002b). There is a relationship between doxa and the dominant classes in that the latter have a vested interest in defending such taken-for-granted beliefs, whilst those with less power would potentially benefit

from exposure of such beliefs. The concept is similar to Husserl's idea of the *natural attitude*, discussed in chapter 2. Doxa became an important theoretical concept during the observations as it became increasingly clear that staff spoke about dying people in ways that were taken-for-granted by them, but not my relatives. The narratives featuring Arthur, Ellen and Dot were key examples of doxa. Crucially, when questioned about various decisions in the context of end-of-life care, few staff were able to explain exactly what it was they had done, or why. Doxa was closely related to the type of dying most commonly seen on the ward. Typically, this was an episode of rapid decline following a prolonged period of uncertainty. The movement of responsibility between the medical and nursing staff followed predictable patterns, which will be explored further later in this chapter.

5.2.3 Field

Bourdieu describes the *field* as:

> *"a network, or configuration, of objective relations between positions. These positions are objectively defined, in their existence and in the determinations they impose upon their occupants, agents or institutions, by their present and potential situation (situs) in the structure of the distribution of species of power (or capital) whose possession commands access to the specific profits that are at stake in the field, as well as by their objective relation to other positions" (Bourdieu and Wacquant 1992, p97)*

The *field* refers to a network of people with shared habitus. Society comprises a network of fields – each of which has a particular internal logic. The ward can be seen as a set of autonomous but related fields occupied by different professional groups and by patients and visitors. Agents within a particular field belong there because of their particular capital. There is a constant struggle to maintain or improve one's position within that field. The field is the context within which the habitus operates. Agents within a field will possess a particular attitude and aptitude which dictates action. Within the field, there are

‘regularities’ in the form of continually reproduced practices, shaped by habitus but also involved in shaping habitus.

Here, the field refers primarily to Bluebell Ward and is bounded by the geographical margins of that space. However, Bourdieu’s notion of field was useful in more ways than just delineating a physical space. It refers to the particular context in which action happened, and also considers how fields interacted within one another. So, nurses were attached to the ward and work set shift patterns. Leaving the ward during a shift was unusual except for specific purposes – fetching a piece of equipment, for example. Doctors worked across a number of wards and their arrival on Bluebell ward heralded a particular change in activity. Allied health professionals such as physiotherapists occupied a field that includes the whole hospital, and they must prioritise their interventions each day according to clinical need. Patients and families occupied a different field; one that was often restricted to a single room. The same applied for the matron, and the site commander. The edges of the various fields occupied were unique, if porous and overlapping. Understanding how the different fields interfaced provided useful perspective on the different practices observed, in particular some of the struggles that took place both within and between fields. This is further explored later in this chapter and in chapter 9.

5.2.4 Capital

A final central concept drawn from Bourdieu is that of *capital*. Capital dictates one’s position within the field. There are five forms of capital. *Economic* and *cultural capital* refer to legitimate knowledge, as acquired through (for example) training as a medical doctor or other professional. *Social capital* describes one’s position as being involved in relationships with other people; nurses acquire social capital through their interactions with patients and their families, matrons hold relationships with those at a hospital managerial level that conveys a degree of social capital upon them within the broader field of the hospital. *Symbolic capital* describes prestige; it is conveyed upon an individual by another individual. Positive public perceptions of doctors are an example of how symbolic capital is transmitted to particular groups in society. Finally, one has a

degree of capital that relates to one's body; this is termed *physical capital*.

Not all forms of capital are equal. There is always a dominant group of people who possess cultural capital that bestows upon them power over other groups. This enables members of that group to define what is considered to be normal - a situation which then dictates how those with less power are expected to act. This also enables the creation of what is considered to be abnormal. There are no objective normal rules that govern societal activity; actions that are considered to be acceptable are only thus because this has been established by the dominant group or class of people. Within the network of fields in the hospital ward, patients are essentially stripped of their social capital; their prior worlds are seldom incorporated into how they are treated. In *Homo Academicus* Bourdieu identifies medicine as a form of social art that *"uses a legitimately invested social power … that is more linked to tradition than to science"* (Bourdieu 1984, cited in Lopes 2013, p821) It is this investment of social power that confers symbolic capital on to doctors and results in the perception that medicine is - in terms of absolute knowledge - superior to other agents within the field of health. As an example, nurses may have acquired symbolic capital by practising at advanced levels, which confer upon them greater cultural capital and hence greater power to act within the field (Lopes, Sobrinho and Costa 2013). However, as discussed earlier older person's medicine is generally poorly perceived within nursing (Cornwell 2012) and none of the nurse participants had undertaken any additional study or qualifications following their core registration degree or diploma, other than that which enabled them to mentor student nurses. As a group, they were restricted in acquiring additional capital that might facilitate greater agency.

5.3 Three Ideologies

Next, I describe three discourses identified in the range of clinical care provided on Bluebell Ward. I present these as ideologies, each informed by a particular set of historical and social circumstances, and consider how each of these were enacted in practice. To do this I apply the theory of each of these to a particular example from the fieldwork, describing an exemplar of that approach to care.

5.3.1 Rescue

Acute Medicine

Patients experiencing acute exacerbations of their conditions, or those admitted with new medical problems, were treated using a traditional acute medical approach. Acute care refers to the *"health system components, or care delivery platforms, used to treat sudden, often unexpected, urgent or emergent episodes of injury and illness that can lead to death or disability without rapid intervention"* (Hirshon *et al.* 2013, p386). An acute care intervention is defined by the urgent temporal nature of intervention, rather than the location of care or the use of technology. This approach is focused on the intended outcome of improving health, which is at the core of the rescue ideology. The model includes trauma care and surgery, emergency care, urgent care, pre-hospital care, critical care and short-term stabilisation.

The Ideology of Rescue

Although hospitals, historically, evolved as places of care for the poor and were run by charitable and religious groups, in recent decades they have become centres of teaching, medical technology and increasing professionalisation. Society often views hospitals as symbols of medical technological progress (Van Der Geest and Finkler 2004; Finkler *et al.* 2008; Mol 2008; Chapple 2010). Chapple (2010) suggests that hospitals recreate broader societal values around heroism and rescue by giving priority to effectiveness and efficiency.

Rescue Exemplar: "Scoring 4 on the MEWS"

The following excerpt from the field notes shows an example of a patient for whom the goal of care was rescue. The title of this section refers to the use of the "Modified Early Warning System", or "MEWS", which aggregates physiological observational data such as blood pressure and pulse, to predict patients at risk of deterioration or death (Cei *et al.* 2009). In the following example, I went with Hannah to see 'David', a patient, who I recalled from having talked with him in the corridor the previous day. I encountered a very different man. The first thing I recall noticing was the odour. This was difficult to describe in words but I remember a mentor, early in my nursing training,

describing it as a ‘poorly smell’. David was drowsy, his eyes sunken, and his upper false teeth had become somewhat detached, dropping to the floor of his mouth. Hannah lifted his blanket to look at his catheter bag, which is bright red with blood:

> *Hannah (to Kirsty): “He’s not for a call[12]”*
>
> *Two doctors arrive - a flurry of questions, palpation, verbalising out loud, looking at his chart. Things are noted which are later explained to me – blood in the catheter bag, sleepiness, low oxygen levels, fast heartbeat*
>
> *Dr Rockwood (to Dr Burton): “Bilateral hernias, nice soft liver, good bowel sounds”*
>
> *Then (to David): “Are you alright?”*
>
> *David raises eyebrows in an effort to open his eyes and nods slowly, then doses off again. Meanwhile, nurses record vital signs – oxygen levels, blood pressure, pulse. All of these parameters are captured on the “MEWS” (Medical Early Warning System) sheet. He’s scoring 4, meaning - requires “immediate medical review”.*
>
> *Within minutes oxygen is given through nasal cannulae. Another tube is inserted into a twisted, tortuous vein on the back of his hand - an infusion of saline to boost his blood pressure. A second drip is started - broad-spectrum antibiotics for what is presumed to be a severe urinary tract infection.*

Throughout this activity, David was oblivious. He remained drowsy and grey. I went home sensing I would not meet him again, but when I returned the following day, I was astonished. David was sitting up in the chair by his bedside,

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[12] This was commonly used language to mean a patient was not for cardiopulmonary resuscitation in the event of a cardiac arrest. It was one of the key pieces of information handed over between shifts, and patients who were not for a call were also identified on the patient whiteboard on the corridor with a magnetic red heart displayed by their names.

drinking a cup of tea, commenting loudly on the activity of the other patients in the bay. I asked Hannah what happened: "*Oh, yes, it was a UTI. He's loads better today".* She was almost dismissive of this, as though it were merely an everyday occurrence on the ward. Which, I reflected, it was.

This event was an example of where the focus of care was narrowed and prioritised with relative ease. Doctors made the decisions, and the nurses enacted them. David's clinical deterioration dictated all activity, with little discussion required. Wordlessly, the nurses gathered up oxygen masks, tubing, fluid monitoring charts, sharps boxes for disposal of needles; the tools of their trade. The miracle of antibiotics is largely taken for granted these days. Seventy years ago, he would have been likely to die.

5.3.2 Rehabilitation

Roberts explained that he chose to work in older people's care because *"geriatrics is the last true generalism. Everyone is a mystery to be solved"*. He enjoyed the *"detective work",* an example of which is shown in the following example, in which Dr Roberts is thinking out loud through the process of differential diagnosis, to an audience of his registrars and myself:

> *Dr Roberts: "So when did she come to hospital to begin with? She comes in, starts this …so she comes in with what they think is a stroke and she goes straight across and she's on Stroke Unit…do we have the stool…so she starts with type 4 and then she goes to type 6…she starts on lansoprazole on 13th…and when did she start the loose stools. She's having type 4 loose stools on 24th and there isn't any evidence that she was having diarrhoea before she was admitted. Well it's probably worth having a look to see if we can find her previous, her baseline if we can. So, she's having type 7 on 16th and when does she go to nursing home…so she goes on 17th. So, it looks like she came to us because.."*

At this point, he took his eyes of his notes and turned to Dr Burton, his junior registrar, and said, "Well?" She floundered a little, and he rescued her with a

detailed explanation of his differential diagnosis. Once finished, the juniors were suitably impressed. A treatment decision had been made and sense created out of chaos.

The Ideology of Rehabilitation

The aims of contemporary geriatric medicine are twofold. Firstly, reversibility, or the accurate identification of reversible conditions in order to avoid inappropriate or burdensome interventions, and secondly, rehabilitation, or the restoration or maximising of function to enable, as far as possible, independence and wellbeing. Rehabilitation aims to narrow the gap between what the patient can do and what the environment requires (Barton and Mulley 2003) necessitating changes to the patient - in the form of medicines and rehabilitation - or to the environment, in the form of home adaptations, changes in the place of care, or increased support. The ideology driving geriatric medicine has been termed **rehabilitation** for the purposes of this discussion, although it includes the element of reversibility discussed above. Obtaining a balance between investigations and treatments was intended to enable avoidance of inappropriate interventions, as suggested by the following extract from the field notes:

> *Dr Roberts introduces himself to a new patient, who is just two months short of her 100th birthday. He palpates her belly, asks questions, notes features of her physical appearance that may offer clues as to her pathology (flushed cheeks, tremor). Outside her room he discusses her lack of formal diagnosis with his cluster of junior doctors. "At nearly 100 I'd look to put her through as few invasive investigations as we can get away with" he concludes.*

Several members of staff from a range of professional backgrounds were at pains to tell me they only worked on the ward because it was part of their training, or because it was the only place where a job was available. Dr Frank told me he hoped to work in *“gastro, where it’s acute. I don’t like care of the elderly; it’s just generalist care really”*. This division between generalist and

specialist care appeared to be associated with a differential degree of capital; doctors working in specialisms were afforded greater status.

Geriatric Medicine

The divided views between geriatric medicine and acute care could to an extent be traced back to the historical roots of older person's care. In the United Kingdom in the early 20th century older people considered 'incurable' were placed in workhouses, institutions largely run by nurses. Here, they lived alongside people with physical and learning disabilities and severe mental health problems. In 1935, when the Isleworth Infirmary adopted responsibility for a neighbouring workhouse, a physician named Marjory Warren assumed responsibility for its management. She found many residents living in squalid conditions and in varying states of neglect and decrepitude. Many had infected pressure sores and signs of mental distress. She began a process of assessment and management that was to later lead to the development of the clinical speciality of geriatric medicine (Warren 1943; Ritch 2012). She recognised that many of these conditions were reversible or treatable, and objected strongly to the notion that old age was a reason for dying in and of itself; a person always dies from some condition or complication. Warren was the first doctor known to implement discharge planning. One of her most significant contributions, which remains a core tenet in geriatric medicine today, was the notion of assessing **rehabilitative potential.** On returning from a visit to Warren's county hospital, George Adams wrote that *"she gave me a practical illustration of what we might one day hope to achieve with the human wreckage in the overcrowded wards of the City Hospital"* (Barton and Mulley 2003, p230-231). Yet it was to be a further thirteen years before the first consultant geriatrician was appointed, and even longer before geriatric medicine was integrated into acute hospital care (Evans 1997).

The first British consultants were in the main located within workhouses and hospices, with restricted access to private medicine. This division contributed to the view at that time by many in other clinical areas that geriatrics was a lesser profession than other specialisms. This professional schism was partly reduced

following widespread recognition that the expertise of the expanding workforce of geriatric medicine could be useful in hospitals, and as their role extended to hospitals, many other specialisms have drawn from the acquired wisdom of geriatrics to apply the principles to their own areas - including rationalisation of treatments reduction of un-necessary medication, rehabilitation and the creation and maintenance of a healthy environment. However, older people's care has perhaps never quite fitted in to the busy acute hospital world, consistently facing challenges in how best to meet the complex needs of older people whilst satisfying the political demands of the hospital and its economy - notably the omnipresent requirement for 'patient flow' and freeing up hospital beds.

Nursing staff had different motivations drawing them to work in older people's care; for some, it was the first place they found work after qualification and they had grown to love it, despite some feeling admitting a level of ambivalence in the early days. For Becky, going into nursing was accidental; she had wanted to enter the police force but for physical reasons was unable to do so. She loved the busyness, the buzz, and the challenge. She hated weekends: *"They're so boring"* she told me. For Kirsty, it was a chance to meet people; she preferred weekends, when there were no doctors' rounds *"and you can just focus on the patients".* Helen hoped to progress in her career, having only recently qualified, but considered that older person's care *"gives you all-round experience in medical"*. For some, the attraction was faith-based or cultural. There were several staff who were born or trained as nurses in countries other than the UK. Alvar, from Spain, entered nursing after caring for his dying grandfather. He told me that caring for older people could be satisfying *"when you can reduce the suffering"*. For Mercy, a devout Christian from Namibia, it was God who sent her to work, to fulfil her duty in helping people to find their strengths. Brett was originally from the Caribbean and had worked in different clinical settings, but loved working with older people because "*they know things. They make you humble."*

Ned's Shepherd's Pie

Ned had dementia and was admitted with a severe chest infection. Initially treated as though he were dying, he had improved over recent days and a new

problem had arisen; the fact that he had not eaten for several days but that he had lost his ability to swallow safely. The following excerpt was taken from a longer conversation between Dr Basu and his daughter, Gail, in the Day Room. It is a particularly lengthy entry because it demonstrates the oscillation that took place while trying to come to the decision, and the various influences upon the doctor and on Gail.

> *Dr Basu: "Your dad, he was admitted with a water infection - his blood tests are showing that he is much better and he has had some but not all of his medicine, because he pulls the cannula out. The only thing he's had since admission is fluid. I know he is 95 but if we don't give him food soon his body will break down, his albumin is already very low and this will get worse. SALT saw him and think that if he eats food it will go into his lungs and cause a chemical pneumonia which is not nice, so there is a big question mark about how now we are going to feed him. If it is by mouth it is a big risk, a big danger. The other better option from a nutritional position would be an NG tube. This is not easy because we have to insert it blind - we would withdraw some gastric fluid and test it to make sure that it is in the right place, and he would have an X-ray to be certain it has passed into his stomach. Antibiotics will be much easier to give this way, but the main problem is that he might pull this out. If he does, we will put it back in again, and if he pulls it out we would put it in again but with a clip to hold it in his nose. A third option is a PEG feed, but this is a very drastic option"*
>
> *Next, he explains the procedure…"we use a light to locate...there is a string...the catheter is withdrawn....the tube is inserted... The advantage here is that you can maintain nutrition. There are some side effects...infection, pulling it out...usually this is done as a last resort", concluding with: "We thought it would be nice before we take action to talk to you"*
>
> *Daughter: "But yesterday he had shepherd's pie...it's not very pleasant, the thought of having a tube"*

Dr Basu: “But to keep someone alive they can only be kept alive for a few days on fluids. We need to think about quality of life. Is he independent?”

Daughter: “I've noticed since my mum's died that he's sort of given up”

Dr Basu: “Has he ever expressed that he's had enough?”

Daughter: “Yes, he has”

Dr Basu: “We try and prolong life with any means we have as doctors. We could take a risk, perhaps give him food and see. If he gets pneumonia he has had a good life but now as you say he is lonely...on the other hand though, he is improving. Confusion is much better and whether he has underlying dementia is another question.”

Daughter: “I don't know how he would react”

Dr Basu: “I think of it as a battlefield, when we have someone in front of me who is moribund we do everything. But my other hat is as a human being...he's 94, lives alone, wife died...is it treating with all the tubes and things that are giving more trouble? The only reason I support the feeding is that he wasn't bedbound, he was mobile. If he had been bedbound, incontinent, needing all cares, I would have been different. I will be guided by you. We can take a risk and feed him by mouth”

Daughter: “It's difficult, isn't it? How long would it be for? Forever?”

Dr Basu: “It's not a pleasant thing, he might pull it would so we'd put a bridle in on the third time and by that time we would make a decision about PEG feeding. IF the tube stays properly...by Monday if we still have to feed him by tube, if he pulls it out at least we'll have done something”

Daughter: “It's difficult, isn't it? Could we not give him a try with food?”

Dr Basu: “Yes, I am probably insisting a bit much...yes if that is

the feeling we will try food"

(Dr Basu turns and asks me what I think. He seems uncertain, and in need of support for this decision. Tricky!! do I answer with researcher hat, nurses hat, or daughter's hat.)

Me: "If it were my dad, he loves food. He would be mortified to think he wasn't allowed to eat anymore"

Dr Basu: "If I was wearing another hat I would agree with Laura"

Daughter: "Yes, I am happy with that"

She leaves.

Dr Basu shrugs and looks at me, clearly concerned. "What can you do?" The junior registrar looks relieved, smiles at me.

A few minutes later, Ned's daughter went into his room and took the NBM[13] sign from the door. *"Guess what dad, they've said you're allowed some lunch",* she said. Ned smiled and said *"Oh, good".* A mug of soup was brought and she began to feed him. He slurped a spoonful, coughed wetly, and smiled. *"I were bloody starving" he sighed.*

5.3.3 Release

In some instances, the transition from recovering or stabilising to dying was uncertain. A person may still have been actively treated in the hope that they might respond, even while they deteriorated. For patients with comorbidities or non-malignant diseases the timing of this transition was particularly ambiguous, and often this meant that dying was identified late (excerpt 1, from an informal conversation over lunch with a group of nurses) or that there was uncertainty regarding how likely the patient was to die (excerpt 2, from an MDT meeting):

1. Rachel: "There was a man in that middle bay, he was a youngish man with a family. The doctors pumped him so full of

[13] *'Nil By Mouth"*

fluid even though he had no output, he literally ballooned, there was fluid on his lungs, his skin was breaking down, it was just awful. It was over the weekend that it got really bad - none of the on-call doctors wanted to make a decision to stop because they were frightened about going against the consultant's orders, they don't want to overrule a consultant decision."

2. Dr Fischer: "The next patient, in 4 - we've had her before"...

Sue: "She's the one who nearly died then didn't then sat about for ages waiting for home…can't recall what they've doing with her treatment-wise…is she dying again?"

Dr Burton: "She's practising…"

The point at which a patient was considered to be 'end of life' was subject to much debate (see for example Christakis and Lamont 2000; Brereton *et al.* 2012; Bristowe *et al.* 2015). Individual patient variables and responses to treatment can confound prognosis, leading to both over- and underestimates. Most of the patients on the ward had chronic long-term conditions, usually more than one which could be considered life-limiting. The point at which a person could be said to be 'dying' was also unclear. A patient could be at the 'end of life' in the terms of the End of Life Care Strategy (implying that they had a prognosis of less than a year), or they could be actively dying, as articulated by the former Liverpool Care Pathway, implying a prognosis of hours to days. Those who were actively dying were much more readily identified than those in their last year of life.

Resuscitation

Authorising dying meant that it was usually necessary to make the decision to withhold cardiopulmonary resuscitation from those for whom it was considered to be futile or harmful. Indeed, an outcome measure for quality of care in the hospital was the proportion of patients who died with a valid 'Do Not Attempt Cardiopulmonary Resuscitation' (DNACPR) order in place. The End of Life Care

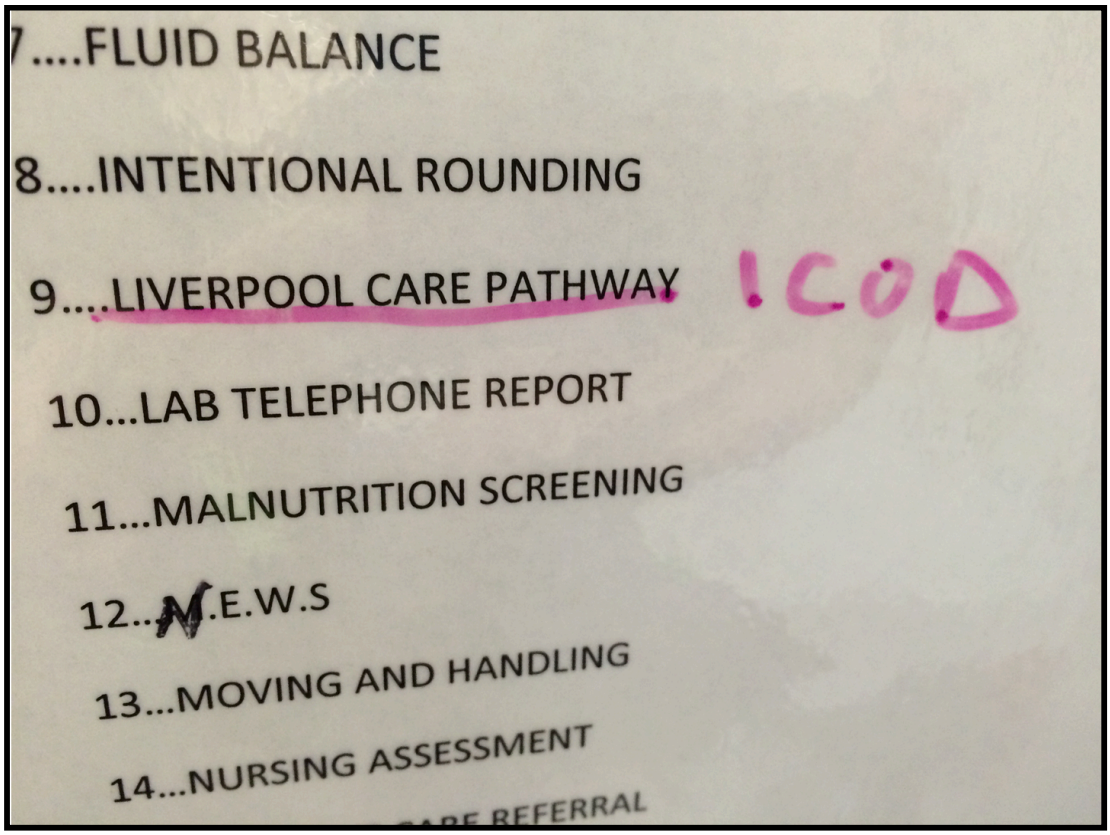
Strategy advocates enhancing the identification of people who are likely to be in the last year of life (Department of Health 2008a). The following field note was written during morning handover:

> *"Bert, not for a call, came in with…Rita, she's still for a call…Paul, not for a call."*
>
> *They are talking about cardiopulmonary resuscitation. Why the euphemism?*

Reflecting later on the above note, I wondered if this happened because some doors are open and patients might hear if the terminology were more accurate. Or perhaps the nurses felt discomfort at speaking out loud of a status that ultimately equates to a decision made that a person's illness is too severe, or their body too frail, to survive cardiopulmonary resuscitation (CPR). Such a life-and-death matter, it had over time become as routine as discussing bowel charts, fluid intake, and other such information.

Identifying those for whom CPR would be unlikely to be beneficial was not an exact science, for the same reasons that presented difficulties in prognostication. Doubts diminished once dying appeared imminent. Care in the last days of life was relatively standardised, and a part of this was issuing a DNACPR form. Although no longer shaped by the Liverpool Care of the Dying Pathway (LCP) which had been withdrawn the previous year (Neuberger *et al.* 2013). In its place, the Integrated Care of the Dying Plan (ICOD) had been implemented in all clinical areas in the hospital; this looked remarkably similar to the LCP and had even been slotted into the same section the filing cabinet (Fig 13). Commencement of the ICOD indicates that the patient was thought to be in their last days of life.

Figure 13: A pathway by any other name



The ICOD gave staff permission to shift the focus of care. Once a patient was commenced on the ICOD the doctor's involvement reduced significantly, and care became almost exclusively the remit of the nurses. When a person was commenced on the care of the dying pathway, nurses were able to follow protocol. The majority of symptoms could be controlled using four 'anticipatory' medications. This seemed to mitigate against any anxiety they may have expressed during the liminal stage where death appeared inevitable but had not been explicitly articulated by the medical team.

The Ideology of Release

The ideology of palliative care relates to ideas of quality of life and the holistic care of people with life-limiting conditions. Core to this is Saunder's notion of 'total pain' (Saunders 2006), which I return to in chapter 8[14]. If a patient's illness was thought to no be longer amenable to curative intervention, there were two

[14] Note that the palliative care 'ideology' has been recently critiqued; see, for example (Randall and Downie 2006; Paley 2014b)

options. If their condition was stable and their prognosis reasonable, the aim was to rehabilitate them to restore their function to a level at which they could function ideally in their usual place of care, but if not, at a level which enabled them to be discharged from the hospital to a different place of care. If, however, their condition was poor or their prognosis guarded, the focus of care shifted to palliation. This change in gear was accompanied by a discernible switch from medicine to nursing in the enactment of day-to-day practices. Once deemed 'palliative', there were certain key medical tasks to be completed. These included signing the 'Do Not Attempt Cardiopulmonary Resuscitation' (DNACPR) order, writing up anticipatory medications for injection in case of common symptoms, and informing the patient's family of their approaching death. Other clinical decisions often also needed to be made, such as the withdrawal of certain treatments that were no longer deemed to be being effective, or the conversion of oral medications to a subcutaneous route. After these medical decisions had been made, care was effectively handed over to the nursing staff:

> *I ask Dr Basu if Dot is his patient. "No", he tells me, "I reviewed her on Friday and have spoken to the family. But she is palliative now".*

I was curious about the *"but".* It implied that she was no longer requiring anything by way of medical input. Releasing a patient from attempt to cure, or rescue means absolving the doctors of their key responsibilities. Often, however, care was transferred to the nurses with some aspect of these tasks left undone. This was a source of irritation and frustration for the nursing staff. The absence of a DNACPR order, for example, could mean that nurses were obliged to perform resuscitation in the event of a cardiopulmonary arrest on a patient who was dying - an intervention which was rarely successful in older patients who were dying and which could therefore be distressing for families and staff alike.

Palliative Medicine

Palliative medicine is a relatively recent addition to the acute hospital care

setting. Palliative medicine was only recognised as a clinical subspecialty in the UK with the establishment of the Association of Palliative Medicine in 1987 (Clark *et al.* 2005; Clark 2016). Two years later the World Health Organization defined palliative care. Five years later it was given status as a specialty in its own right. Today, specialist palliative care is provided in many settings, and even though hospice care continues to be promoted as the 'gold standard' for end-of-life care, the provision of care for dying people in acute hospital settings is firmly embedded in policy at least, if not yet fully in practice (Department of Health 2015; National End of Life Care Programme 2015).

The nurses varied in how they felt about caring for people who were dying. One lunchtime I spoke with Rebecca and Salina (a bank nurse) about what it felt like to be around someone who was dying - especially if they deteriorated suddenly:

> *"I get butterflies in my stomach and feel sick" says Rebecca. "But I think it happens less and less the more you work here." Salina is a bank nurse - tells me that this is hard because everyone assumes you have already seen and done everything. She vividly describes seeing a patient die of internal haemorrhaging, vomiting thick, jet-black coffee ground vomit. She describes how she sat in a room on the ward, quietly, feeling very afraid. I ask what happened next. "After that, I got strong", she tells me, "and now I don't mind." During a separate conversation, Sonia, a healthcare assistant, told me that she once came on shift and asked, "where's bed 21?" and she had died during the night. "I mean, I knew she was going, but not when. And it was all, like, business as usual." …*

Paul: "The Gift of a Good Death"

Transition from acute care to a palliative approach did not take place until what was commonly referred to as '*the conversation'* has taken place. There was a shared understanding that this refers to a difficult conversation in the context of end of life care. The following excerpt is an example of *the conversation*; it took

place in much the same way whenever a patient was deemed to be dying. In the example the patient, Edward, was very close to death. The consultant introduced himself.

> *Dr Roberts: "What have you been told so far?"*
>
> *Son: "That his kidneys are weak and his heart is not working and that to treat one means harming the other and that they have reached the end of treatment really"*
>
> *Dr Roberts; "And what are you expecting?"*
>
> *Son: "Well, that's it, now. He told me 6 months ago that he was quite happy and ready to join my mum"*
>
> *Daughter: "He's distressed at the moment"*
>
> *Dr Roberts: "It is clear that he is getting close to the end of life but it sounds as though he is prepared for that. Death is never good, we always want more. But we don't want to prolong things, we wish now to give him the gift of a good death"*
>
> *…*
>
> *Daughter: "He's 93 but even so, we keep telling ourselves…but still..."*
>
> *Son: "I think in years to come there'll be too many old people and you'll need to..."*
>
> *Daughter (quickly): "Just keep him comfortable, won't you, keep him quiet"*
>
> *Becky (staff nurse): "I'll go and start the syringe driver now"*

Following this conversation, the doctor began to complete the ICOD and the nurse left the room to collect the medications and equipment to commence the syringe driver. The powerful rhetoric in offering *"the gift of a good death"* served an important purpose here. It framed what was happening as inevitable but located and defined the role of the clinical team in making the experience a positive one. His daughter's priorities throughout the conversation were to

restore comfort; at times, she seemed agitated at how long things were taking, and when Dr Roberts eventually mentioned the word *"death"* seemed almost relieved. This relief was shared by the nurse who was waiting by the bedside for an indication to commence medications to settle him. Paul's daughter's request to *"keep him comfortable"* was that permission.

5.4 Disciplines as Ideological

Bourdieu cautions against efforts to over-interpret, instead suggesting that the sociological task of his theory of practice is to examine the dialectical relations between the so-called objective structures which can be accessed by objectivist knowledge, and the *"structured dispositions in which those objects are actualised and which tend to reproduce them"* (Bourdieu 1972, p3). This is an important link between symbolic structures and actions. According to Bourdieu, habitus informs actions dependent on the degree to which agents are possessed by (as opposed to in possession of) their internalised world view. Habitus as a generative principle produces practices which reproduce certain regularities. So, patterns that were seen in the enactment of the various ideological positions, can be considered generative of habitus, rather than objective aspects of reality that can be described and therefore predicted. The idea of habitus was particularly valuable because it offered insight into situations in which individuals were neither guided purely by their own free will, but nor did they automatically enact of societal structures. Instead, there were internalised form of societal values which influenced behaviour within a particular field, and sets of values varied between individuals and professional groups. Differences between individual practitioners, and in different situations, with different patients, attested to the unique nature of agents within the field.

Bourdieu suggests that habitus is situated outside consciousness; that the reproduction of discourse takes place habitually and often in the absence of cognitive intent. This may partly explain why when asked directly about their perspectives on care of the dying, participants were unable to readily describe what they do, and why they do it. Care appeared to be given as a result of assessing not only the particulars of each patient scenario but also according to a particular set of beliefs or ideology pertaining to the goal of care. Each

ideology was associated, albeit not exclusively, with different professional values and shared common-sense understanding of how they ought to go about their practices. Habitus was unconscious, although agents may become conscious of some ways in which they reproduce objective meanings. The different professionals on the ward each 'inherit' a particular legacy, a professional discourse that dictates their interpretation of their circumstances and predicts their responses.

Thus, in the scenario described above, we saw practices that arose as a result of the interplay between the situation and the habitus of the doctor. Not every doctor would respond in this way to this scenario, and even this doctor might respond differently in another encounter with a dying person. Bourdieu's position allows for this by demonstrating that an individual's habitus is not only comprised of their shared understanding with others in their social group, but their own stock of experiences, social position and education. The scenario was used here not to argue for generalisable explanatory potency, but to deepen insight into how adopting a critical sociological perspective can offer alternative perspectives that challenge the idea of agency and individualism that dominates so much of our current cultural formations.

5.5 Ideological Tensions

I now consider what happens when things were not quite so straightforward. For example, what happened when (as was common) the reversibility of an acute deterioration could not be predicted, or when different professionals were in disagreement about the appropriate approach to care. To explore the problematic edges around these ideologies I discuss two examples of tensions or conflicts between ideologies. The first examines what happened in an environment of uncertainty, and postulates that the default position was rescue. The second example explores transition - when a patient's condition changed, necessitating a change to care. This was not necessarily a coordinated process, with different members of the team making the transition at different times. In both of these examples, I suggest that these tensions could have caused or exacerbated patient suffering.

5.5.1 Comorbidities and the 'Recursive Cascade'

Issues around social functioning were frequently at the forefront of patients' minds. The acute model of care was difficult to apply when a patient's problems were social or functional. In such instances, when asked what medical professionals can do to help them, patients may be at best baffled, and at worst confrontational:

> *Doris (to me): "I'm here because I had a fall. I could go home but family don't want it. They're trying to keep me safe. I don't like it. The noise! I moved from Scotland to be near my daughters but it didn't make me any better".*
>
> *(The nurse comes in)*
>
> *Diane: "Is there anything you need? Are you in pain? Do you want a paracetamol?"*
>
> *Doris: "No, thank you" (angrily)*

Hospital care of older people is complex. Alongside acute events there are often chronic conditions that make clinical care challenging. Acute hospital treatment, often for a single prioritised condition, can fail to take into account the confounding influence of these other problems. The focus on rehabilitation within geriatric medicine could be problematic in the hospital setting. Rescue was prioritised which could mean that rehabilitative approaches were delayed until a patient was medically stabilised. For older people who may take longer to recover from acute illnesses this could mean prolonged bed rest and deconditioning, leading to loss of function and reduced rehabilitative potential. This is a frequent cause for concern within the physiotherapy and occupational therapy literature (Clift 2017). The idea of returning to 'normal' function is problematic when a patient has stayed in the hospital for a long period. Warren and Manderson (2008) observe that the discourse of 'normal function' is problematic when patients in a hospital experience increasingly complex health issues. Their notion of *'recursive cascades'* (Manderson and Warren 2016) refers to a pattern of hospital stay for older people that is characterised by *"one*

thing after another" (p479). There was rarely a clear point at which a patient can be deemed medically stable. Often, one comorbidity will be resolved or improved, only to find that another problem arises. This can lead to extended hospital stays which in turn can be associated with a range of functional and clinical problems.

Furthermore, problems were seldom if ever solely medical. Among an array of reasons for admission to hospital people may be failing to cope with existing social and practical support at home. Indeed, this was so common that it had acquired its own unofficial name on the ward- never written in the notes, but often quoted in the nursing handover and the multidisciplinary meetings – *'acopia'.* The 'a-' referred to the Greek prefix common in medical terminology, meaning "without". This word was thus intended to literally mean 'without coping' and to function as a pseudo-scientific way to convey the situation of a patient being admitted without specific medical needs.

5.5.2 Changing Lanes

One concern with the acute care or rescue model of care was that it could be difficult to identify the appropriate time to stop or withdraw active treatments when they were futile, no longer effective or potentially harmful. Ellen, who is discussed further in chapter 7, presented a poignant example of suffering resulting directly from a delay in making the transition from curative to palliative care. Hers was not an isolated example; after she died, I spoke to a group of nurses about their opinions on her care. Kirsty described the following:

> *"Sometimes we are forced to do DNACPR because of acute illness. It shouldn't be a decision based on age but I think sometimes if you've got so many ailments and background that you suffer with…. We had a lady admitted and I said - and the physio agreed, and the reg - that she would not be getting out of here alive. But they still carried on doing things to her, almost like she was a guinea pig for the doctors, for statistics, I don't know.*

She was full of fluid, her kidneys were knackered, she had heart failure and they couldn't balance the medications without causing one thing or another to start failing. You couldn't get rid of the fluid, and you could see she was done for. She'd had a CVA too, could hardly walk. Nobody asked her if she wanted to be left alone in relation to the treatments she was having. Mind you, she wasn't one to speak for herself, sometimes patients just accept that doctors just do stuff. But you just knew with her."

This extract identifies three concerns; the patient's comorbidities, aligned with various social issues resulting from her frailty such as difficulty walking, were seemingly separate from the core motivation for rescue. Once that cascade was set in motion it became difficult to know when to stop. The concerns that Kirsty described here are common in nurses providing end-of-life care acute settings (Wotton *et al.* 2005; Thompson *et al.* 2006; Bloomer *et al.* 2011). Nursing may feel frustrated and morally disturbed when a lane change is not possible.

The onus was upon medical staff to make the decision that a patient had become 'palliative'. Some found this transition difficult and this meant that *The Conversation* (in which this news is broached with family members) could become challenging or – as in the following example – fraught with contradiction and conflict:

Jane (Ellen's daughter): "She seems to have got worse"

Dr Frank: "She's been here 11 days and obviously we didn't know why. We passed her NG tube to make sure she got nutrition. She is being monitored and the usual path is improvement. When not improving we look for a specialty to come and help us - like last week when we got Dr X from the Stroke Team. So, we use different specialties for different things. We saw her today again and we don't think she is improving so we are wondering if we should get people from palliative team to make her more comfortable…"

Jane: "What will palliative care do?"

Dr Frank: "Comfort"

Jane: "But that's what you are doing anyway…"

Dr Frank: "We are involving another specialism, we stop unnecessary treatment, prescribe meds if she's in pain"

Jane: "How will you know if she's in pain?"

Dr Frank: "We look in her eyes, you can tell, if I pull your arm here I see in your eyes. So, we'll give her something if she's vomiting. But we don't lose anything by getting specialist team to look at her, may consider ICOD pathway, we haven't reached that yet"

Jane: "I don't think I've seen her like this"

Dr Frank: "At the same time we'll get palliative care in, she shouldn't be in pain…basically we are doing everything we should and I'll get the specialist team to look at her. If we think she's not improving and she's dying then we put her on a pathway"

Jane: "So what does that involve?"

Dr Frank: "But for now we haven't reached there, I'm getting a lot of people involved. Do you have any questions?"

Jane: "I'm concerned that she is uncomfortable"

Dr Frank: "Palliative care professionals are trained to recognise agitation better than us"

Jane: "I'm worried that she is agitated and distressed"

Dr Frank: "We can give her diamorphine for pain, midazolam for agitation, haloperidol for vomiting and buscopan for secretions prn, based on our judgments, I'm going to prescribe them now while we wait for the palliative care consultant"

Jane: "I'd like you to try more. Chest drain, antibiotics, maybe I don't want to face it but she's just being left there"

Dr Frank: "She's been on antibiotics"

Jane: (begins to cry)

The continuous tension between rescue release is evident in this excerpt. The questions posed by Jane (such as what was involved in putting her mother *"on a pathway")* were not answered by Dr Frank. It seems that his discomfort around the transition to dying was mitigated by ongoing efforts towards rescue. These were precisely the kinds of conversations which were found to be lacking in the investigations into failures in implementation of the Liverpool Care Pathway. Doubtless, such topics cause distress both to the instigator and the receiver of such information. Later that day in the corridor he mentioned to me, almost in passing, that Ellen *"could not keep bouncing back for the rest of her life."*

Research suggests that transitioning from curative to palliative is easier when there is "compelling clinical evidence" that recovery was not possible, and when patients and their families were actively involved (Thompson *et al.* 2006). Other studies confirm that clinicians often find it difficult to acknowledge when treatment is no longer working (Chan and Webster 2010) and this can lead to moral distress (see for example Oberle and Hughes 2001; Back *et al.* 2015). As medical and technological advances continue to progress, there is increased blurring between what is considered to be a reversible medical problem, and what is a natural consequence of advancing age (Van Hooft 1998; Dunphy 2000; Back *et al.* 2015). Efforts to cure patients vary between medical settings, with the hospital offering the highest intensity of technological and medical intervention. As medical technology expands, so does the likelihood of being able to reverse conditions. Even within chronic illnesses once considered terminal, there are opportunities for extending life expectancy and managing exacerbations and crises. The lines between rescue, rehabilitation and the natural process of ageing and dying are increasingly blurred. Choices about when to intervene were rarely clear, but it appears that - at least in this case - the default position was to treat unless it is universally accepted that a particular treatment is likely to be futile (Kaufman 2005, 2015).

Conflicts in care occasionally arose as a consequence of being unclear as to the overarching goals of care. The tensions between forms of power at play between competing individuals and their ideologies were not unidirectional. Scripts could be reversed and social capital can be acquired by nurses adhering to the ideology of rescue. When a patient was clearly and unequivocally dying, and had resisted attempts to rescue, the power inherent in the ideology of rescue appeared to diminish and the nursing profession (who shared the terminology and practices associated with end of life care) appeared to acquire additional capital.

5.5.3 The Conversation

There was a tendency for doctors to talk to families of dying patients using a variation of a core script (which I have called *The Conversation*). There was little deviation from the content of this script. Indeed, there was tacit recognition of this patterned way of speaking about such topics as nurses would often refer to *The Conversation* and would each grasp immediately what this was meant to imply. Talk of *The Conversation* invariably contained such discussions as whether or not the patient was "*for a call"* (for cardiopulmonary resuscitation).

To adopt Bourdieu's notion of habitus is to see this kind of event as an example of when practices arise that are *"patterned after the social structures that formed them"* (Wacquant 2013) and are characterised by an 'inbuilt inertia' (Navarro 2007). The situation of speaking with families of dying people presented a particular set of challenges, and habitus provided the rules by which doctors navigated this challenging terrain. The inertia of habitus testified to the way that *The Conversation* served its required purpose. In each case it appeared to follow a broadly similar structure and give the impression of being a script of sorts. This was despite the heterogeneity of the dying trajectory and individual patient and family experience that makes every encounter with dying unique.

The following excerpt demonstrates the way in which some doctors appeared to find the transition from curative to palliative treatment difficult. The two doctors

in the excerpt looked and sounded uncomfortable throughout this observation, that took place as they both re-evaluated their role in the care of a patient who when last seen was being treated for a chest infection, but had been 'put on the ICOD' the previous evening as he was thought to be dying. Paul had advanced dementia and a bilateral pneumonia that has not responded to intravenous antibiotics. I was informed at handover that morning that the doctors would see him and his daughter to have *"the conversation".* I had been sitting with Paul and his daughter for the hour before the doctors arrive. His cheeks were sunken, eyes rolled back in his head. His daughter, red-eyed, was draped against the pillow, stroking his cheek. His breathing was ragged.

> *Dr Basu enters with Dr Burton, wheeling notes trolley in front of him. Dr Basu leafed through the notes, underlines something. Dr Burton peers over his shoulder:*
>
> *Dr B: "the full sepsis bundle" (Sighs. Walks to bedside)*
>
> *Dr B (to Paul who is unconscious): "Good morning. We have met before" (Unsurprisingly, no reply).*
>
> *He examines him, pulls eyelids back, listens to his chest. Cheynes-Stokes breathing[15]. He instructs Dr Burton to make a note to the effect that Paul was "comfortable".*
>
> *Dr Basu (turning to Paul's daughter): "I'm sure the nurses have had a conversation with you. They have told you that our plan is to keep him comfortable".*
>
> *She nodded, her face a kaleidoscope of grief, exhaustion and something else. Was it anger? We left the room and before moving on to the next patient, the Consultant again consulted the notes.*
>
> *"I'm sure we have seen him before", he repeats, turning back in*

---

[15] Cheynes-Stokes respiration is an abnormal breathing pattern that characterises instinctual, brain stem breathing. It features progressively deeper breaths followed by a period of no breathing. In this case it was caused by imminent death although clinically there are other reasons for it.

the medical notes. “Cause of death will be pneumonia”, he tells his Registrar, Dr Burton, who clarifies “sepsis secondary to pneumonia”. “I think pneumonia will be sufficient. And dementia.” “Are we doing observations?” Dr Burton asks. Dr Basu shakes his head. “He is on the pathway, I don’t think he is going to last very long”. He sighs, murmurs “anyway”, and replaces the file in its appropriate slot on the trolley before entering the next room.

Where habitus matched the field, the doctors were comfortable. The patient manifested the kinds of problems that fitted with their expectations and fell within the physician’s professional remit to alleviate. However, when the rules were changed by forces outside their control - in Paul’s case, because the antibiotics had not worked and he had entered the dying phase of his illness - a struggle resulted, in which the medic sought to regain equilibrium. When death approached, the resources at their disposal were severely curtailed - in fact, they were limited to two primary functions. Firstly, as doctors they could prescribe ‘anticipatory’ medications (injectable drugs to palliate the most common symptoms experienced in the last hours and days of life, such as pain, death rattle, and agitation). Secondly, they were expected to complete the death certificate. The former function requires little in the way of clinical decision-making, as the drugs of choice during the terminal phase were generally established by local policy. The latter function did, however, require a degree of clinical skill, hence the extended conversation between the consultant and registrar regarding the death certificate. They were referring to a situation that has not yet arisen; Paul was still breathing.

Beyond this, their role was undefined. They removed themselves from the difficult situation, leaving an unsatisfactory open-ended event that appeared to have no therapeutic value to either Paul or to his daughter. There was a shift in the symbolic capital at the point where the medical profession could no longer direct the outcome. The kinds of interactions described above have also been identified in other observational work on end of life care. For example, Sudnow (1967) observed practices in which dying patients were talked about as though already dead, even to the point of having their eyelids closed whilst still

breathing. Taken in abstraction and in another context, the conversation between the medics regarding Paul's death certificate could be seen as ludicrous, even grotesque. He was breathing his last breaths whilst holding on to life, and the doctors were concerned over the documentation of cause of death. Yet in the context of the hospital, and aided by the actual and symbolic barrier between Paul's death bed and the busy, ordinary corridor outside his room, the conversation does not seem out of place. A final reflection in relation to Paul was that the team were unanimously in agreement that his was 'a good death'. Yet this was not Ruth's perception.

5.6 Conclusion

The three ideologies described were broadly aligned with the three clinical disciplines of acute care, geriatric medicine and palliative medicine. Although all three clinical disciplines were nominally physician-led, the shared values of each ideology resonate more strongly with some professional groups than others. For example, geriatric medicine's strong emphasis on rehabilitation and maximising function means that there was a natural place within the specialism for the allied health professionals, specifically physiotherapists and occupational therapists. Acute medicine, with its emphasis on diagnosis and cure, was dominated by physicians. Palliative care does not have quite such clear professional 'ownership', but its origins illustrate that it was largely nursing led until its recognition as a distinct medical specialism in the 1980s. As such, it was reasonable to presume that nurses have a traditional relationship with caring for dying people that was newer and less integrated within the medical professional identity.

The dominant ideology refers to the belief system reproduced by the most powerful members within a particular society, that enables the oppression of individuals within that society (Abercrombie *et al.* 1990). Cultural (in this case medical) hegemony leads to many members of society accepting the tenets of the dominant ideology often without question. The hospital is often portrayed as an iconic institution of medical expertise and traditionally doctors hold the power within the hospital walls. In this study, recent political changes within the health services had seen a shift in this balance of power such that doctors held

relatively less sway over everyday practices, and this power was largely held by hospital managers. However, on the ward itself, doctors retained power over the other clinical and allied professionals. Multiprofessional working, generally considered to be exemplary practice in older people's care, was often fraught with difficulty as a consequence of such power imbalances. This reproduced a situation whereby those without power enable the dominant ideology to continue to reproduce patterns of practice.

The point at which a person was dying was the point at which the acute ideology was enfeebled, and the medical model failed to produce solutions. At such moments, efforts were made by doctors to mitigate against the damaging effects of this unmasking. Devolving responsibility to nursing staff was one mechanism by which this mitigation took place. Another was to make use of the remaining medical processes and technologies - the syringe driver, the treatment algorithm, the 'Do Not Resuscitate' order - in order to seek restoration of power. These processes and technologies were what Bourdieu might refer to as the kinds of symbolic systems that usually helps to consolidate ideas of dominance, the objects of symbolic capital. The mobilisation of these resources can be seen as an assertion (or a reassertion) of power in the face of the existential threat posed by the dying person. This pattern could also be understood by considering the extent to which contemporary medical practice is 'death-denying'. Although beyond the scope of the current thesis, it has been argued that Western society is generally death-denying (Becker 1973; Zimmermann and Rodin 2004; Walter 2014) and medical practice reflects these wider societal values.

The ideological conflicts described can also be seen as social practices, that are influenced by power relationship between members of the multidisciplinary team. The direction of care, and the decisions that are made, appear to be influenced by the interplay between these ideological positions. Viewing these dynamic interactions as a manifestation of habitus may illuminate phenomena such as inertia in clinical practices. Whilst great progress is being made towards understanding the constituents of 'good care', bad care remains highly resistant to change. The social order is continuously reproduced by the enactment of

capital.

These practices in caring for older people at the end of their lives took place within a broader societal context which continued to hold that dying was primarily a medical event. The dominant, rescue model of care denied complexity by seeking reductionist explanations for the kinds of suffering experienced. Opportunities to improve practice were everywhere; yet the resources to enable them were not. These opportunities were locked into sets of objective circumstances within which agents' freedom to act were structurally constrained.

In the next chapter I turn to the participants themselves and examine the phenomenon of suffering in context. The influence of the ideologies of care remains apparent but the spotlight turns to the patients' experiences themselves. This is to make suggestions regarding how these competing ideologies impact directly on patients.

Chapter 6: Here, there is nobody

> *"In the field, one has to face a chaos of facts…in this crude form they are not scientific facts at all; they are absolutely elusive, and can only be fixed by interpretation" (Malinowski 1916/1948, quoted in* Geertz 1988*, p81)*
>
> *"Yo soy yo y mis circumstancias" ["I am myself and my circumstances"]* (Ortega Y Gasset 1914/2004)

6.1 Introduction

This chapter introduces the first group of participants[16]. Field notes relating to each patient have been organised into individual narratives. For each participant, key themes relating to suffering have been identified and supported by using extracts from the fieldwork. Each account attends to a different aspect of suffering, and although each narrative stands alone, there were common themes which I have drawn together in the conclusion. Theory will be drawn upon lightly, for the purposes of contextualisation rather than abstract concept development. It is my hope that the stories will speak for themselves, the pictures of suffering that were portrayed were vivid accounts of what was witnessed. I have not yet introduced the broader literature relating to the nature of suffering. This is because I intend to let the data lead the analysis [17] whilst also acknowledging that there is *"no view from nowhere"* (Nagel 1989). Prior to starting the field work I was already familiar with some of the literature, but decided to set it aside during the data collection return to it after analysis. This was to avoid shoehorning my findings into that which was already known.

[16] For full list of participants see Appendix 3 and 4

[17] This body of scholarship will be introduced in chapter 8

Figure 14: Here, there is nobody

I considered each of these participants to have been suffering. Some told me of their experiences directly; others hinted through story or expression or non-verbal behaviour. Their accounts have been used here to address the following key questions:

1. What was the nature of suffering for patients on the ward?
2. How do participants conceptualise their experiences?
3. What was the broader context for their suffering experience?

This is an interpretive account of those words, behaviour, sounds, smells, sights and actions that resonated with me, and that taught me something of the multiple nature of suffering. I chose encounters and events by following Mason's (2002) suggestion that when researching one's own practice, one should pay attention to *"brief but vivid"* moments acknowledging that *"there is choice in what I notice, a selection from the totality of the unreflected upon, the primary experience"* (Riessman 1993. p222) I aim to *show* rather than *tell* these stories. Identifying and exploring suffering was easier with some patients than with others; this sometimes related to how verbally articulate the participant was, but other times it was more to do with their receptivity to my presence, or

an ambiguity to nonverbal expression. Rita was a bright, sharp and witty woman, continuously watching the activities around her. She was bored and keen for company, and spoke in detail about her experiences. In contrast, Vincent was contented to let me sit in his room but by his own admission was *"not a talker"*. Much of his suffering experience I gleaned from observing his interactions with staff, rather than through direct conversation with him, although in the latter days of the study this shifted and he initiated several brief conversations about mortality. Michael was withdrawn, some might say depressed, and he offered little in the way of verbal interaction. But his face was often an open book. Much of his experience was described through the sounds and expressions he made in response to encounters with myself and staff.

The key participant for the chapter was Vincent. This was because his suffering captured something that typified many of the other participants' experiences. Also, a significantly greater time was spent with him than with the other participants. This was in part because of pragmatic reasons - his hospital admission was the longest. He had arrived the day before I began observations, and died three days after I left. I was therefore able to observe almost his entire journey. It was also because Vincent was alone almost all of the time. Only on one occasion was there a visitor which led to me leaving the room. There was extensive opportunity to spend time with him, which provided both a rich source of data, and ongoing companionship for a lonely and dying man.

6.2 Vincent: "Making a Drama Out of a Question Mark"

Vincent was 84, admitted to the ward with an exacerbation of his long-standing chronic obstructive pulmonary disease (COPD). He lived alone, having been widowed six years previously in a car accident in which he was the driver. Following the accident, he had awoken in Intensive Care to discover she had died. Since then he had shunned nearly all attempts at helping him, although he had been taking mirtazapine (an antidepressant) which had been prescribed before he was discharged home after the accident. At home, he passed the time listening to the radio, watching television and smoking cigars. He had few close friends or relatives, but was visited regularly by a neighbour, Andrew. He

was gaunt; his movements were slow. His long beard was nicotine-stained. His chronic cough caused frequent paroxysms that left him exhausted. During this admission, his COPD had been treated with intravenous antibiotics and oral steroids. At three different times during his five-week admission he was deemed to be “medically fit” for discharge, but each time this decision was revoked. Twice this was because he developed a further acute medical problem, and once because there were concerns about his safety at home - he smoked cigars yet required long-term oxygen, and he had not ‘complied’ with physiotherapy and was felt to be unsafe ascending his stairs.

We had a conversation about consent but I was not sure that he fully understands; he didn’t really want me to explain, said he can’t be bothered. So, I ask him whether he would be happy for me to sit and spend some time with him, that I am researching how the different people in the team provide care for him. He shrugs. I have seen him eject people in no uncertain terms when he doesn’t want them around, so I take this as consent and mentally make a note of trying to explain the study a bit more later if he gives me the opportunity.

> *Little eye contact at first - looks at me suspiciously. Interrupted by Rebecca who, apologising for the intrusion, says “I’ve just come to do your tablets”. He rolls his eyes at me. I am aware that I am supposed to be observing interactions but right now it feels right to try and engage with him. When she leaves we talk about his wife, about relationships, the reasons they didn’t have children, he told me about the day they met at a dance, musing out loud how differently life might have ended up if her house wasn’t in the same direction as his “we ended up walking home together that night”. He describes the companionship that characterised their marriage, how they would often think of something at the same time and say, “I was just thinking the same thing”. His voice tails off and he leans back. “What’s the point of having this bone marrow thing?” I ask him if he wants to feel better, and he tells me “every day I think ‘tomorrow might be better’ and then I wake up next day it isn’t, and I get disappointed but I’m not surprised. I just can’t be bothered"*

We mostly sat in silence. His breathing was noisy and bubbly, his chest mottled, ribs protruding. He often sighed. He stared straight ahead. His pyjamas usually gaped open, his catheter bag on the bed next to him. He clutched a tissue in a shaking hand. Antibiotics were becoming progressively less effective at dealing with his frequent infections:

> *I find myself sometimes forgetting to breathe as I watch the rhythm of his chest, and listen to the bubbling sounds of his breathing, punctuated by liquid coughs, an occasional louder sound as he expectorates yellow-green mucous into a tissue which he replaces on the bed table.*

It was not just Vincent's lungs that were failing. Each treatment for his lungs entailed giving him steroids, to enhance the resilience of his lungs towards the bacteria. One of the side effects of steroids is muscle wasting; his legs were thin and weak, and wobbled visibly whenever he tried to stand.

6.2.1 Losing Independence: "It's a Distant Place to Me Now"

It was common practice to discuss individual patients with nursing and other staff outside the room before they enter. On one occasion, the team discussed that Vincent had "*failed stairs",* had a presumed diagnosis of MDS (myelodyplastic syndrome) which would be likely to lead to repeated anaemia, and was a smoker but seemed unaware of safety issues. They were all in broad agreement that he was unsafe to go home. They then entered his room, ostensibly to ask his opinion on the matter:

> *Dr Rockwood: let me ask you a very serious question…you have this problem with your blood, some problems with your chest …taking everything into consideration do you feel you can manage at home?*
>
> *V: yes*
>
> *Dr: is that where you want to go?*

V: yes

Dr Rockwood: in order to get home you will have to cooperate with the physio…I know you have some pain but we have given you paracetamol, yes?…anything to ask?

V: yes, I want to go

This interaction was framed in such a way as to suggest that there are likely to be problems with going home. The "*very serious question"* and the fact that the doctor repeated his question "*is that where you want to go?"* belied an underlying sense that this was not the answer he sought. Over time, concerns over safety meant that Vincent experienced multiple assessments by various professionals tasked with enabling him to go home safely, but each time there were problems raised until he became increasingly aware that going home would not be as straightforward as he had originally hoped. His fear about coping was compounded when he was asked questions.

Jo (Social Worker): "I am here to help get you some help at home. Are you wanting to go home?"

V: "It must be better than being here"

J: "The carers I can set up for you will be excellent"

V: "In here they're marvellous. There's toast whenever you want it"

J: "Well that's what I'm here to help with, to make sure this care continues when you are home....What about washing and dressing?"

V: "Oh, I shall certainly need that"

J: "They're called the re-ablement team. That means they will try not to take away your independence, just to give you help when you need it. They'll do as much or as little as you tell them, just what you need. Is that okay?"

V: (Laughs – but cynically, there is no humour. His eyes are

blank. He looks away, stops eating his trifle and stares at a blank spot on the wall)

J: "Is that what you want?"

V: "Anything love, anything" (resigned slump. She leaves)

Vincent was torn between a desperate need to get home to his former normality, and fear about how he would cope. His ambivalence was exemplified in the apparent contradiction: *"it must be better than being here"*, followed closely by *"in here they're marvellous".*

Sometimes interactions that detracted from Vincent's independence, or else implied an increasing level of need, led to expressions of anger or frustration. In the following excerpt, Claire (a student nurse) enters with a wash bowl and flannel. On seeing me by the bedside she backs away:

St/N: "I'll come back, I were going to give you a wash"

V – "Yippee. Yippee. I'll enjoy a wash (faking enthusiasm) I'm kidding. I'm not telling the truth"

(apologetically when he sees student nurse looking flustered) "I just get a bit stressed up worrying about it all"

Again, in the following extract Vincent was talking with Jo, a social worker about his exact care requirements when something that is said triggers an angered response:

Jo: "Do you think you'd like 4 carers a day?"

V: (stares straight ahead) "Too much"

Jo: "Three?"

V: "Once in a morning and then leave me be"

Jo: "What about your evening meals?"

V: "No, I don't want anybody"

Jo: "What about bedtime?"

V: (angrily turns to look at her) "I don't want anybody in my home at bedtime! I want to bloody go upstairs, switch on the electric blanket, smoke a cigar, put it out, go to bed"

During his admission, Vincent gradually surrendered his autonomy as decisions relating to his future were taken on by different professionals. The excerpts suggest he was both aware of this and simultaneously powerless to do anything about it. In the following conversation, he describes the sense of continuously waiting - although for what, he cannot say:

Vincent: "I just want each hour to pass. I'm stuck like a pig in a poke"

Me: "What would you do if you were at home?"

V: "Sit on the sofa, watch the telly, lock the front door. Go upstairs, switch the blanket on 10 minutes before I go in" [eye contact, looks at me, frowns and rolls his eyes, appears angry]

Me: "Are you cross?"

V: "I'm always cross. I'm a cross person. I don't know when, why, what is going to happen"

Me: "Is going home the most important thing for you?"

V: "No"

Me: "What else is, then?"

V: "I don't know, I'm just waiting, don't know what's happening, and you don't know either" [coughs, liquid] (lifts legs up and lets them flop down again. Eye contact only when angry, rest of time stare fixed ahead).

6.2.2 Choicelessness

Time after time, the decision for Vincent to go home was revoked for one

reason or another. On one occasion, it was because his blood results have come back abnormal. Routine blood tests revealed an abnormality thought to be unrelated to his primary condition; he was severely anaemic. Doctors were concerned that he had myelodysplasia, a precursor to leukaemia. A repeat blood test was ordered to ascertain the anaemia's severity. A definitive diagnosis could only be gained through a bone marrow biopsy, which Vincent was offered but declined (this aspect of his care is discussed further in Iatrogenic Suffering).

The absence of a diagnosis contributed to Vincent's 'unimaginable futures' (Kaufman 2006, p198). Vincent was invited to consent to investigation based on the probability that the disease, if diagnosed, was treatable. Doctors were quick to point out that MDS is a precursor to leukaemia that may or may not develop into the full-blown malignancy. Even if it were to develop doctors could not estimate the potential timescale for this conversion and there was every likelihood that Vincent would deteriorate and die from his existing advanced respiratory disease prior to then. So, in the absence of leukaemia, the treatable element of MDS was to have repeated blood transfusions to manage the anaemia.

This made sense on one level; anaemia can cause fatigue and breathlessness, and these were already serious problems for Vincent that impacted daily on his quality of life and sense of wellbeing. However, the likelihood would be that he would require regular admissions to hospital for transfusions and given the recursive cascade he had undergone on this admission it would be unlikely that he would ever be admitted for a simple intervention like a transfusion. In summary then Vincent was being asked to make a choice about an investigation for a disease which may or may not become life-threatening, and for which the ongoing treatment may or may not be feasible. Given that he had already expressed ambivalence about being in hospital in the first instance and a determination to avoid coming back in again, coupled with his fears about the investigative procedure itself, it was easy to see the root of his reluctance. It was not mere belligerence. Choicelessness framed as choice was a recurrent theme in Vincent's care. Often, he had little or no agency in what was happening, and yet was presented with various choices as though he were in

control. It appears that he was well aware of this choiceless state hence his resistance to many of the apparent choices he was offered.

Vincent's frustration with the many changes in plan were most apparent at night, when he frequently becomes agitated and angry – most often because he was apparently trying to leave the ward to smoke a cigar:

> *It is 1:20 in the morning. V is on the move again. Keelie, a healthcare assistant, finds him leaning in the frame of the doorway to his room.*
>
> *K: "You're not going anywhere if you hurt yourself"*
>
> *V: "I want to see my friends, they'll be wondering where I am. Where's all my money and my keys?"*
>
> *K: "I do understand, sweetheart"*
>
> *V: "What do you bloody understand?"*
>
> *K: "That you want to go home"*
>
> *V: "They'll bloody change their minds again tomorrow"*
>
> *K: "No, they won't. Now go to sleep, there's no transport to take you home now, it's the middle of the night. I don't drive so I can't take you"*
>
> *V: (loudly now) "I just want a bloody cigar"*
>
> *K: "You can't smoke in hospital"*
>
> *V: "Course you bloody can"*
>
> *Pam, the senior nurse, comes in:*
>
> *Pam: "The facts are these: you're going home in a few hours, we can't get you home now, if you keep acting like this you'll make yourself poorly. Calm down now and get some sleep. The doctors going to come and see you to make sure that your hip is okay. Do you want your light off?"*
>
> *V: "No" (turns over)*
>
> *Pam, to me and Keelie: "It's all so complicated, this mental*

capacity thing. Like, he's got his wits around him during the day but still, earlier we had a chat and he was happy about going home. I reassured him about his money, and like now he's forgotten and he's got himself into such a state and I just think about his stairs at home…"

He is calming down now. I sit with him and listen to him wondering out loud: "Can I manage at home? Can I get up and down the steps?"

He falls asleep.

While on the ward he fell numerous times, most usually at night when disorientated and trying to go outside for a cigar. He would get out of bed, momentarily forgetting that his body was too weak to walk. Staff were aware of his smoking and there was some talk about nicotine replacement., but this didn't happen; Vincent laughed that you can't compare a patch to a cigar. They viewed his agitation as a physiological withdrawal from nicotine, but for Vincent, cigar smoking seemed more than that. It was a symbol of normality and autonomy:

"Sometimes… I just want to lift a cigar to my lips, light the bloody thing, and inhale" (slowly)…(he leans back, closes his eyes, and smiles) "…like normal."

6.2.3 Uncertainty: "Making a drama out of a question mark"

Vincent received mixed messages about whether or not he was going to get better. For example, when he declined the bone marrow biopsy, the doctors cautioned him that he would not get better; this was a source of some confusion as the anaemia was not the problem for which he had been admitted to hospital, it had been an additional finding on investigations once his presenting disease had been treated. Vincent's perception about getting better was informed not only by the medics. The rehabilitation assistant who encouraged him to get out of bed echoed this by telling him that if he did not mobilise he would not get better. Of course, the rehabilitation assistant was referring to his

strength and functional status rather than his disease. The nurses, trying to set up an intravenous infusion of antibiotics for an infective exacerbation of his COPD, suggested that it was important for him to have this medicine so that he could get better, and in this they were referring to his chest infection. Vincent's idea of 'better' could not be mapped to any of these three interventions and he had unanswered and unanswerable questions:

> *V: "I just wish it were done with, all this palaver getting home. Why hasn't it happened? [grimaces] oh never mind, I'm making a drama out of a question mark. I don't want to make the decision. I want someone else to do that. Just MAKE the decision what to do next"*

It was not only Vincent who was dealing with the consequences of uncertainty regarding his future. Confusion regarding the plan of care was reflected in many of his interactions. The following extract demonstrates a mixed message that Vincent was both too poorly to go home yet too stable to stay in hospital. His interpretation of being told that he was fit to go home was that he would immediately be discharged. However, this did not happen, as there remained numerous further bureaucratic processes that required attending to. His suffering notably increased at this point; home had been promised, and not delivered. Subsequently, his nights became more agitated, and his interactions became angrier:

> *Vincent: "I want to go. I want my own place"*
>
> *Louise: "You're going in the morning"*
>
> *V: "It's bloody morning now"*
>
> *(Louise has asked for Nick, a healthcare assistant (HCA), to sit with him as she is concerned about his increasing risk of falls.*
>
> *V: (waking, suddenly) "What is this place?"*
>
> *Nick: "Try and get some sleep"*
>
> *V: "What for?"*
>
> *N: "Because you are poorly, you are not well and you need to have a rest. Try and have some rest"*

V: "Why?"

N: "Because you are poorly"

V: "I was but they told me I could go, they released me yesterday"

The following extract illustrates a paradox. Vincent was determined to go home often expressing this with some vehemence. At the same time, he was fearful of doing so because of a range of issues including security, his ability to self-care, privacy and money. Staff sought to identify practical solutions to his concerns, but occasionally this meant that his expressed concerns were overlooked, as happens in the following extract where his use of humour belied a sense in which he was gradually surrendering his autonomy. The following response to Social Worker Jo's questions suggested resignation and surrender to this crowd of professionals, each charged with helping Vincent perform a different daily function[18] :

Jo: "Has anything changed? Do you still want washing and dressing?"

Vincent: "I need help with everything now"

Anne (Social Worker): "Do you want more help? … How many times a day would you like?"

V: "I don't know, love"

A: "Four times a day? If you need help with everything….you've been in here for a while now. Do you need help with medicines?"

V: "Yes"

A: "And meals?"

V: "Yes"

[18] The issue of personhood and the role of depersonalisation in iatrogenic suffering will be further explored in chapter 9.

A: “And toilet?”

V: “Yes, it’s hard work. Make me an offer I can’t refuse” (laughs, wryly)

A: “So, up, washed, dressed, toilet, medicines, catheter care...”

V: “Form an orderly queue outside” (laughs again)

A: “I’ll put this forward to assessment”

6.2.4 Vulnerability

A further facet of Vincent's uncertainty was a perpetual feeling of vulnerability. He readily admitted that he felt frightened. There were certain predictable triggers to this including the prospect of going home and the potential for his property to be at risk of theft. One day he told me that he felt fearful about going home because of the thought of people breaking into his home while he was too weak to defend it. One night a patient from another room walked into his room by mistake. Vincent was frightened and helpless and in his disorientated drowsy state had presumed the intruder to be a thief. The next day, he asked the nursing staff several times to report the incident to security. Each time he was reassured that the intruder was no more than a lost patient. That afternoon, the doctors reviewed him, but the incident was still clearly on his mind.
A few days later a healthcare support worker found he had been hiding his wallet containing a large amount of money under his pillow. Staff were keen to put it into safekeeping, but he again expressed fears that it would disappear.

V: "Have you seen the thief?"

Me: "What thief?"

V: "That elderly gentleman who comes in here"

We talk about it. It sounds like a patient came into the room, but V realised it wasn't a thief but a lost patient

V: "Terrible thing, mental illness" (finishes porridge, lies down. Trolley wheels rattle, locker beeps and whirrs as the nurse gets out his medication)

Nurse peeps head around door: I understand there's a wallet in here with rather a lot of money – picks it up from bed table

V: "I want it in my pocket"

Nurse: "It'll be safer locked away. We will take it to the office for safekeeping"

V: "Just give it to me"

Nurse (opens purse, looks inside): "What do you need all that

for?"

V: (shrugs) "Safest with me"

6.2.5 Grief

Vincent often spoke of his wife. His grief, four years after her death, remained palpable. He recalled driving to France with poles and a canvas and setting up tent in the shade of a cypress grove with her. He told me how their words seemed to pre-empt one another's and that there was never a cross word exchanged between them. They never had children – he shrugged and told me it never seemed to be what they were about. *"She were the love of my life"*, he would say. His most recent mental health review followed an observation from the physios that he was *"low in mood and self-deprecating"*. The mental health worker documented that he showed many *"depressive symptoms"* including *"early morning wakening, poor motivation, issues around grief, regular thoughts about suicide, has considered hanging himself but afraid of being unsuccessful and being in pain…"* She noted that he was *"socially isolated, neighbours help out…a loner and prefers it that way." Her summary of the assessment was "as physical condition improves his mood might too…no further input from MH services…ring if needed etc."* The following entry, by an FY1 Doctor, stated that Vincent appeared clinically stable, somewhat contradicting the view from Mental Health services that his mood could be ascribed to his physical condition. Vincent had a good appetite and usually cleared his plate. This was often taken by staff as a proxy indicator of wellbeing. Yet one of the most common side effects of mirtazapine is increased appetite and weight gain. This increased appetite was not necessarily accompanied by enjoyment of food. Vincent often ate while staring straight ahead spooning food into his mouth and swallowing without appearing to even taste it.

Staff appeared uncomfortable faced with his low affect and his lack of communicativeness. They often recoursed to jollying him along as in the following excerpt:

Dr Roberts (kneels beside V): "I noticed yesterday that you were constipated, we've increased the laxatives but nothing has happened as yet"

D: shrugs, does not make eye contact

Dr R: "You look down in the dumps. Fed up. Miserable"

D: "I'm like that all the time"

Dr R: "Well let's see what we can do about getting you a bit brighter"

There was an existential quality to Vincent's suffering. Occasionally he spoke directly about this. The following conversation took place around a week before his death:

Me: "How are you?"

V: "You know" (shrugs)

Me: "I don't know"

V: "Thinking about it all..."

Me: "About what?"

V: "You know. How long all this is going to last"

Me: "What do you mean?"

V: "How long before the end"

Me: "Do you mean before you die?"

V: "Yes, love"

Me: "Have you been thinking about that a lot?"

V: "Well you can't not, really. You lie here and they do this and that...and some days I feel alright and like I'm getting stronger and back on my feet and other times" (closes eyes, flops head to one side, mimicking death)

Me: "You think about which way you're going?"

V: "Well you only get one go at it, one shot. Unless you recover from being really ill, I think you only get one try"

Me: "That's true. Unless you believe in reincarnation I suppose"

V: "No, I don't. I think we are just dust. Or compost"

Me: "Do you worry about it?"

V: "Ooh no, it's just what happens"

Me: "You're no stranger to it, really, you've talked about people you have lost"

V: "She were the love of my life. Ah well," (we sit in silence. There is a rattle outside the door) "Is that breakfast? This is a bit morbid. I'll have my porridge now"

Me: "Thank you for talking to me"

V: "It's nice to talk about it. Nobody here talks about that. They just do things"

6.2.6 Last impressions

The following extract was written three days before Vincent died.

Lying on bed, trousers open, net pants visible, twisted around his legs. His long legs are folded awkwardly to one side. Semi-recumbent, stares straight ahead, with that gasping breath of his. One breath: two sounds. his mouth looking as though it is trying to gulp the air, and a deeper, bubbling in his chest, that sounds like there is a cough waiting, but doesn't come because he is too weak. "I didn't think you'd still be here today" I tell him. "well I went home in the night but I decided to come back" he replies. I'm not sure if he is joking or not.

He looks up at me. I am writing.

"Are you going to turn that into a book?" he asks "Maybe", I reply, "I'm not sure many people will read 100,000 words about people in a hospital." He tells me his neighbour wrote a book,

and it sold for £7 but she only got about 8 pence per copy. He shakes his head. Smiles at me. Hangs his head and closes his eyes.

When I arrived the next day, I was told he had got up in the night again to try and have a cigar. He had fallen again, only this time had fractured his pelvis. He had been taken for emergency surgery to pin the damaged bone, and from there to an orthopaedic ward for rehabilitation. I was told that he had died there two days later, but I never found out the cause of death. This upset me deeply; having spent so much time getting to know him, I wanted to understand how his life had ended. Perhaps the preceding uncertainties had evoked a need for clarity and finality for me, a neat ending to the narrative. He might have had a sudden acute event, such as a blood clot. Or perhaps his lungs, weakened by having been under anaesthetic, succumbed to a further infection that he was unable to defend against. In any case, I would never know the end of his story.

Although burdened by the symptoms of his disease, Vincent's rarely complained of his cough, fatigue or weakness. His suffering was related to ongoing uncertainty about his future. This uncertainty was itself comprised of numerous elements; the uncertainty of his diagnosis, prognosis and recovery, uncertainty regarding going home and uncertainty pertaining to his safety and security. During his hospitalisation he became progressively weaker, succumbing to further infective exacerbations. One after the other, obstacles arose, either relating to his physical condition or to issues around care. From the day he arrived, it was never quite clear whether he would be able to go home and his autonomy and agency were gradually eroded. As each obstacle arose it became clearer and clearer that going home was an increasingly unobtainable goal, a *distant place.* The behaviours that hinted at his suffering included irritability, withdrawal and non-compliance. He never described his suffering directly but alluded to it in terms that were frequently existential, peppered with references to doubt, uncertainty and fear. His suffering was palpable in both his verbal and his nonverbal language but all that could be offered was screening for depression. Suffering was never addressed specifically. It was invisible, or remained in peripheral vision such that staff felt discomfort or dissonance about something, which usually led to them withdrawing from the relationship or seeking out quick solutions – replacement

nicotine, a definitive answer regarding plans for home, or a change in dose of his antidepressant.

Staff had aimed to rehabilitate Vincent to the point of going home; each time he was deemed medically stable, something happened to prevent this. Through discussing his daily care needs, and liaising with the occupational therapists, decisions were made about the kinds of risks he would be exposed to in his daily activities - how he would get to the bed, use the toilet, prepare his meals, and so on. But for Vincent, discharge represented a starting point of the next stage of his life. The hospital admission had been a liminal zone, a period of waiting and anticipating, where the treatments he received and the investigations he endured were seen as incidentals rather than the focus of his admission. His future unfurled as an alarming and unknowable path, and one which he admitted he could not imagine. In the interceding time, however, things had taken their own paths and his life had ended in hospital. He never did get to smoke another cigar.

6.3 Florence: "And the Rest of Me Too?"

Florence had bilateral leg ulcers, and a bowel infection that caused frequent and uncontrollable diarrhoea, nausea and vomiting. As the door to her room was opened, a foetid odour emerged. She was an overweight woman, dressed in a hospital-issue nightdress. She lay in bed most of the day. She had been admitted for management of the two infections and had received intravenous antibiotics for this purpose. When Florence was comfortable she conversed readily. She made wry observations and comments about her situation. She told me a story about when she used to be a credit collector, recalling the most ridiculous excuses she came across for reasons people defaulted on payment: *"The best one I ever heard was a woman who said she hadn't paid it back because her lightbulb had gone and she couldn't see to write out the cheque".*

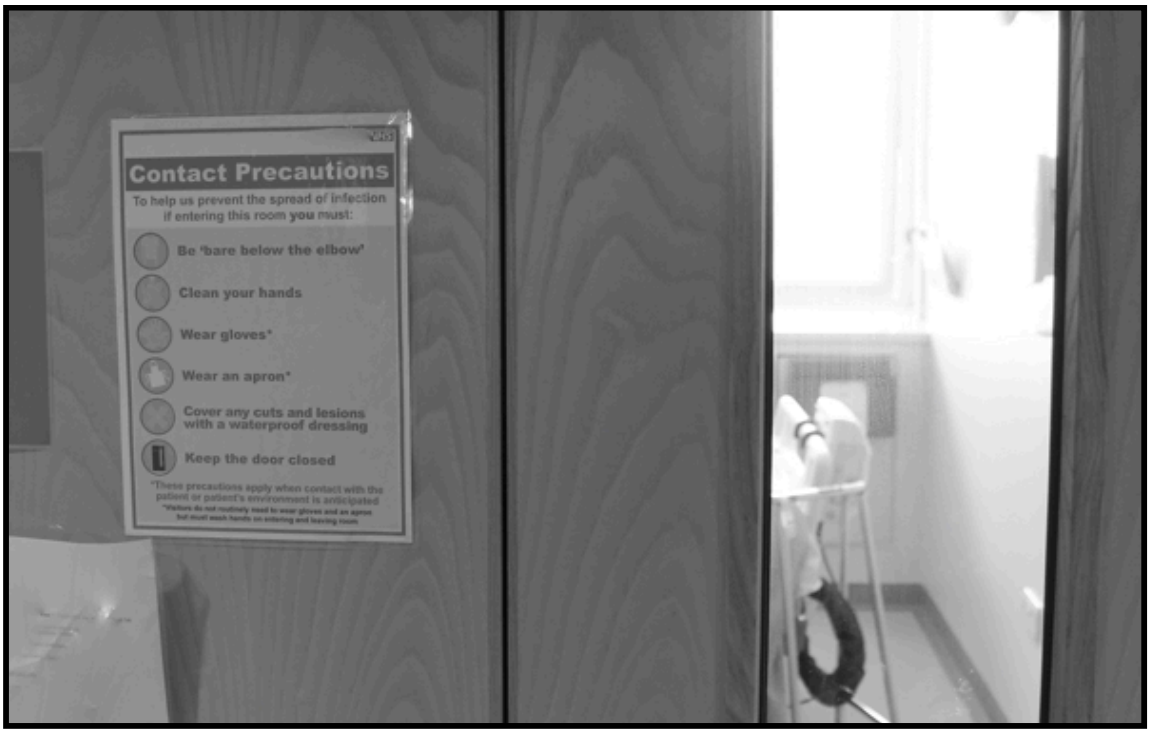
Florence experienced daily severe pain when the wound dressings to her leg ulcers were changed. Replacing dressings involved slow removal with saline of

the existing dressings that often adhered to her red raw broken skin, followed by irrigation of the wounds, followed by tight rebandaging of both legs. Florence expressed pain loudly: she cried, suffered palpitations and panic attacks, her breathing was rapid and she sweated profusely. This often began some time before the dressings were actually changed, indicating that an aspect of her pain was fearful anticipation of the actual physical pain. She had begun to request higher and higher doses of analgesia before her dressing changes; staff were increasingly alarmed at the potential for addiction. The dose had therefore been capped pending a review by the chronic pain team - for which there was known to be a wait of several weeks.

6.3.1 Alienation

My impression was of an isolated and alienated woman. She was symbolically separated from her family, and literally separated from the ward as a result of being in a side room. All contact had to comply with ‘barrier nursing’ principles for infection control (Figure 15). The door to the room had to be kept closed. ‘Contact precautions’ had to be taken by anyone in contact with her, whether or not they have actual physical contact with her body. This included a white plastic disposable apron, and blue disposable nitrile or rubber gloves. The strict infection control measures served to protect staff and other patients from cross-contamination, yet they had a profoundly isolating effect.

Figure 15: Contact Precautions



These had to be disposed of in the Clinical Waste bin before exiting the room, marked with a bright orange 'biohazard' symbol. On several occasions, I observed how this approach to her care left her feeling degraded and humiliated. The following excerpts are from a reflective piece I wrote after witnessing an encounter with a senior registrar:

> *Pippa, the senior registrar, examines Florence, who has been admitted with infected leg ulcers. She has tested positive for the C Diff gene and has been 'symptomatic', in other words, has been experiencing severe diarrhoea. She is in a single side room and the hospital policy stipulates that the door has to remain closed at all times, and that anyone going in must wear protective clothing - a white plastic pinafore, and pale blue nitrile gloves. As the registrar talks to her, she stands by the bedside, her arms folded. Florence complains that her belly hurts and the Registrar visibly blanches. She asks her junior whether there are any disposable stethoscopes on the ward. When she is told that there are not, she realises she must use her own stethoscope. She performs the required examination rapidly, reassures*

Florence that "everything sounds okay, some good bowel sounds there" and walks briskly to the foot-pedal bin where she disposes of her pinafore and gloves. Outside Florence's room, she wipes the bell of the stethoscope repeatedly with sterilising alcohol gel, wrinkling her nose while she does so.

6.3.2 Loss of Hope

The main plan for Florence was to cure her infections. The other focus was on rehabilitating her so that she would be well enough to go home. Staff were concerned that this was increasingly unlikely and that she was 'giving up':

One of the nurses emerges from Florence's room, quietly closing the door behind her. She has just finished changing the wound dressings on Florence's legs. The sister asks how she is doing, and the nurse replies "it's like she doesn't want to make progress, like she's giving up. You have to talk to her now to get her to talk to you; before, she would ask you stuff. It's like she's lost everything". The sister responds that Florence has been in the hospital for a long time. "All her obs are fine, nothing acute happening, but she's just giving up. It's sad, really."

Staff tried to encourage her to sit out of bed, to encourage her to build up strength and independence. The mental health team had concluded that she was "*very much taking on a sick role*" through her reluctance to get out of bed. Staff were concerned about how little effort Florence was making to walk. She had been discharged from the physiotherapy service because the pain from her legs prevented her from doing the prescribed exercises.

On one occasion when the sister was giving her morning tablets, I observed the following interaction:

Sue (ward sister): "Let's get these legs out of bed today, yes

Flo?"

Florence: "And the rest of me too?"

(both laugh)

Intended as a joke, this interaction nonetheless points to the ongoing imperative for staff to emphasise rehabilitation. This interaction is further examined in chapter 9 where I consider the potential for interactions to cause suffering. The humour in Florence's response appears to be a relief for both of them but it also indicates poignantly how the focus on one part of her body risks inadvertently disconnecting her as a person. Her body – or rather, the sum of problematic body parts – becomes the focus of care.

The general perception among staff was that she was gradually becoming more and more dependent which went against the grain of the agenda in which patients were rehabilitated and discharged as fast as possible. When patients did not also share this goal, it led to tension and conflict:

> *Rebecca (about Florence): "I don't mean to sound mean but she's not helping herself. Her husband is on at her too about needing to walk again, and she's not ever even really sick". Conversely, patients who know the rules demonstrate at least an intention to walk, even if they lack the ability. They then earn approval from staff, as overheard when staff were marvelling at the fit and motivated 98-year-old patient admitted the previous day: "She's really good, this lady, she just wants to get going".*

Florence's perspective was predictably somewhat different. She pointed at her legs and told me how the pain felt as though her skin were on fire. Her eyes filled with tears as she described what the wounds looked like underneath the bandages. She did not think they were improving and was gradually trying to get her head around the possibility that she faced the prospect of daily wound dressings for the rest of her life. Her wounds signified her suffering, but it was not purely physical. Her face visibly recoiled at the odour as the bandages were

removed, and she averted her eyes from the sight of the raw weeping flesh. I asked her what her current goal was, and she told me *“to get through the day”.* Getting back upon her feet was low in her list of priorities at this time.

6.4 Rita: “I’m Fed Up of The Nothing”

During her 94 years, Rita had acquired four children across two marriages. She was stoical in the true sense of the word. She was a slight, hunched woman with short grey hair and startling blue eyes, deep in a craggy, wrinkled face whose topography suggested a great many smiles and frowns. With end-stage heart failure, she now required oxygen through a nasal cannula, and her sentences were often punctuated with gasps and pauses. Her fingers were gnarled with arthritis, pointing in every direction except that intended as she wagged them emphatically. Despite the effort in conversation, Rita enjoyed meaningful interaction greatly.

> *“I’m fed up”, she says. “It’s like this”, and she draws a long line in the air with her finger. “They don’t tell you what is wrong with you. Something’s failing, I can feel it.”*
>
> *I ask what she has been told, and she tells me it is heart failure. But this is all she knows. She resents having to hear her heart being spoken about out loud in a shared bay of patients;*
>
> *“It’s not public information. Everyone can hear. They think I don’t want to know, but my feet are on the ground and my head is on my shoulders, not in the clouds.”*
>
> *“Do you like things being told to you straight?” I ask. She nods. “Yes, just like it is. I know I’m going but they don’t tell you. They talk about me as though I am invisible, as though I am not even here. It’s like the information doesn’t belong to you. But this is me” - she points at her chest. Then she leans back against her pillow. “I’m fed up of the nothing”.*

When I spoke to Rita she told me several times of her anger about not having been included in discussions about her illness. She tells me that the doctors arrived and listened to her chest, rummaged through her notes and charts, scribbled something on her prescription chart and left, swishing the curtain closed again behind them. From inside the curtain, she heard them discussing her 'case'. She couldn't remember what they said, but recalled specific words - heart failure, titration, meds, oxygen. They had left without explaining anything to her, or giving her an update about when she might be able to go home. The impact of being excluded from clinical discussions in this way can be seen as iatrogenic suffering. Although burdened by physical symptoms such as her breathlessness, and the pain from her arthritis, the issue Rita attested to repeatedly was the suffering that resulted from being spoken about as though she were absent - or worse, as though she did not have the ability to understand what was being talked about.

6.4.1 Disempowerment: "As if I don't know this body"

Rita's husband has a marginal role in her world. She refers to him with pity, as a nursing home resident who has *"lost interest in people"*. For her this was a defining feature of being alive, to maintain one's sense of social reality. By comparing herself with her husband, Rita reveals the human trait that she equates with carrying on, with not giving up - that of being interested in people. That Rita's social world was so important was evident in the vehemence of her reaction to being apparently ignored by the doctors; she felt that she had been framed as a non-person. Her assumption was that they had treated her as they might treat an older person who was lacking in mental capacity. Their actions deprived Rita of social capital. Being interested in people conveyed a sense of how important relationality was to her. She interacted regularly with others for the purpose of interest alone. In the hospital, the purpose of the majority of interactions were clinical, brief, perfunctory. Curiously, when given an opportunity to speak to one of the doctors about her concerns, Rita declined. This may have reflected a sense of pointlessness, a recognition that relations between them had now been established, that she did not have faith that she would be given the responses that she seeks - the opportunity to be treated as

an equal, to find that the doctors were interested in her as a person and not just as a disease to be treated.

On the walls behind patients' beds were small whiteboards, for their names and consultant. At the bottom was an extra section that reads *"what is important to me"*. Most of the whiteboards were blank. Rita's reads *"coffee in a real china cup"*. Most of the warm drinks for patients were served in plastic mugs, blue or brown in colour. Patients with shaky hands or a tendency to spill things were given theirs in clear plastic cups with tightly fitted sip lids to prevent spillage. The drinks were cooled before handing out to reduce the risk of scalding. I made myself a cup of tea in a patient cup; I was told off by one of the healthcare assistants. *"They're for patients, not staff. Infection control"*. I made it anyway, and sat in the staff room to drink it.

6.5 Alfie: "Watching the bloody clock"

Alfie was nearly seventy and something of a mystery. He arrived on the ward having been sent in by his GP following admitting that he had taken an overdose. In A&E it transpired that no overdose was taken, but he was drowsy and sweating, and he was admitted to the ward for observation, taking the bed opposite Ned. He had numerous life-limiting illnesses: poorly managed diabetes and renal failure. His blood sugar regularly fluctuated from dangerously high, putting him at risk of a potentially fatal hyperosmotic hyperglycaemic state, to dangerously low, where a lack of sugar to the brain can lead to coma and death. He would not eat, drink or take medications, or allow his blood sugar to be tested. He was taciturn and testy, seemed suspicious of each and every member of staff:

> *07:40am, staff nurse asks Alfie how he slept:*
>
> *A: "you bloody people, I've had two people checking the exact same thing today, I was up at 2am with doctors seeing him" [he gestures towards Ned, in the opposite bed]…*
>
> *Nurse: "We just want to do the best for you"*

A (seems to ignore her): "That nurse who was on last night blackmailed me to have medicine, she knew she was off today"

(Nurse flinches, her lips tighten, and she moves swiftly on to the next patient)

Alfie was young in comparison to many people on the ward. He was admitted following an attempted suicide but assessed as not suicidal whilst in Accident & Emergency. However, he then collapsed, and was transferred to the ward for investigations which had been inconclusive. Alfie was suffering in the absence of a diagnosis, which uncertainty compounded the situation. He felt unsafe on the ward, ill at ease, and angry. He was a medical enigma with a cluster of curious symptoms - unexplained transient loss of consciousness, anorexia, confusion, and profound weakness. He had pain in both legs presumed to be related to his diabetes yet investigations excluded this. He gave a different history to each medical professional who tried to assess him. His responses to the nursing staff were largely curt and clipped.

At times his drowsiness became so severe that he would become completely unarousable for a period of time, not even responding to staff when blood tests were taken or oxygen clips attached to his finger. During these episodes, his eyes were glazed and staring, his mouth open, his body floppy and pliant. Then he would spontaneously return to normal and bark at the nurses to go away and leave him alone (which they hurriedly did). When he was asked what he wanted, he would always say *"home"*. Sometimes he accepted my presence and we talked; he told me which of the nurses he trusts the least, and which were out to get him. At other times, he scowled when I approach him. At these times I left him alone, gleaning snippets about what was happening for Alfie through conversations overheard outside his room.

During one of the weekly multidisciplinary team meetings, the staff discuss his potential diagnosis. *"Functional",* the consultant suggests – a word generally used to describe any presentation of symptoms that cannot be ascribed to a physical cause. At one time, his presentation might have been described as psychosomatic, and there was even talk of Munchausen's Syndrome, but it was

more politic to describe unexplained symptoms as functional. There was clear discomfort among the staff at this. Dr Roberts took a £5 note from his pocket and waved it at the gathered staff. *"This is for anyone who can tell me what is going on with this man."* The team laughed, but nervously. His junior doctors looked uncomfortable. The nurses were exasperated - *"if we are not doing anything for him, why is he blocking a bed that could be used by someone more deserving?".*

6.5.1 Boredom

One day, when asked how he was feeling, Alfie told me: *"I'm just watching the bloody clock. Tick, tick. I don't know why I'm here, I want to go home."* The nurses had told him he can't go home until he was 'compliant' with treatment. *"It's just not safe"*, they told me. They were concerned about the effect of not eating on his diabetes. Alfie had no control over his situation. He was bored, confused and frustrated. He had little leverage to influence what was happening to him. His only way of controlling thing was to refuse to comply with treatment. Paradoxically, it was this that was delaying his discharge home, and so he and the staff were caught in an ongoing struggle for power. I was mystified as to why staff were so reluctant to permit him to go home.

The reason was revealed to me one morning in a conversation with Brett, a staff nurse: *"if we send him home, it will be a failed discharge."*

6.5.2 Uncertainty

Staff found it challenging to look after him. He did not want anything to be done, but as each day passes it was increasingly clear he was unwell. His encephalogram report read:

> *"EEG[19] is abnormal due to background slowing from excessive and intermixed, intermittent delta/theta activities from both*

[19] *Electroencephalography*

hemispheres in wakefulness" …"aetiologically nonspecific abnormal findings suggesting bihemispheric cerebral dysfunction"…the letter goes on to explain that this may be seen in certain encephalopathies, and some neurodegenerative disorders.

I asked the neurologist what this means. *"No clear diagnosis but a few possibilities. We would need to do further tests",* he tells me.

After a week of being in hospital undergoing various (inconclusive) tests, an MDT was held. One of the doctors suggested sertraline, an antidepressant, but Dr Roberts was reluctant to give what he calls *"black magic drugs*" without a clear rationale. Alfie did not agree to see the mental health team, so no diagnosis of depression has been made. A nurse commented that his blackouts appear to be voluntary:

"one morning he were out of bed having a cup of tea and he asked if I could help him back to bed and I said 'just finish your cup of tea' and because I wouldn't put him back to bed he went like this (gesticulates) flung his arms out and started going (gurgles) like that. And anyway, I put him back to bed and as soon as he knew I were putting him back to bed he stopped doing it".

Without a clear diagnosis, some doctors were uneasy, but others described his 'case' as a *"refreshing change from the usual falls and chest infections."* The nurses consider that he was 'blocking a bed' and suffering from mental illness with *"nothing actually wrong with him at all".* Other staff think that he was trying to kill himself through starvation and plans to stay in the hospital until he dies. *"He knows exactly what he was doing"*, I am told, *"but I kind of think - if you want to die, go home to die."* For the nurses, hospital was not the right place for him to be cared for.

One day, I arrived on the ward to find that Alfie had self-discharged - two weeks

after admission, with no definitive diagnosis. The nurses shrugged, rolled their eyes and got on with their day's tasks. During his stay, he endured nerve conduction studies, an electroencephalogram, blood sugar monitoring (when he was too drowsy to decline), urine and blood tests, and a screening for infection. None of these found any physical cause for his drowsiness and blackouts. He had visibly lost weight. I wondered out loud how he has managed to stay alive with no food or drink, and one of the healthcare support workers muttered *"oh, he ate, but only when we weren't looking."* No pathological cause for his cluster of symptoms was found, and none of the staff connected with his emotional or his spiritual suffering. Alfie's story was left unfinished.

6.6 Michael: "Just Put Me on The Scrapheap"

I asked the nurses which patients at that time they would describe as suffering. Kirsty pointed at the door of room 2. *"Michael",* she said without hesitation.

> *"He has pressure sores all over him, incontinence, depression. He's come from supported accommodation where carers saw him four times a day, they usually found him lying in his own excrement because he was faecally incontinent. If I were in his position I'd want someone to put a bullet to my head. Earlier I had to give him a suppository and I apologised first, I said "sorry, this is going to be a bit uncomfortable", and he said "nowt new there. Just put me on the scrapheap""*

Michael was a quiet man in his late seventies. He came into the ward from a warden-controlled housing. When he arrived, his state was - according to one staff nurse - *"shocking".* Malnourished, with a grade four decubitus ulcer to his sacrum, and wearing soiled pyjamas, he hungrily swallowed the soup offered to him. His hands shook as he spooned it into his mouth, and lumps were caught in his tangled beard. Doubly incontinent and unable to walk, Michael had been utterly reliant on three carer visits a day. At home, these visits had usually been

brief and functional. Carers often found him lying in his own excrement. His incontinence meant that the pressure sore, regularly covered in excrement, had worsened to the degree that at the bottom of the gaping wound, it was possible to see only a thin layer of connective tissue over the bony prominence of his sacrum. The wound was the size of a fist. He required regular suppositories and enemas to manage his chronic constipation, but these usually led to faecal matter oozing into the wound which caused agonising pain. His response to the physical pain was to clench his eyes closed and turn his face into his pillow. He rarely spoke. Sweat beaded on his face and neck until the wound had been cleaned out with gauze and saline and the soiled adhesive dressing replaced. The wound dressing needed replacing whenever there was a leakage of faeces, which was usually at least daily. I observed the procedure several times. As the nurse arrived pushing the trundling dressing trolley and equipment, he showed no visible reaction. This was a marked contrast to Florence's anxious and tearful response when her wounds were dressed. Michael appeared resigned, surrendered, and powerless. The nurses had insight into how painful the procedure must have been, and always apologised beforehand. They often looked uncomfortable as they enter the room, only to smile brightly at Michael as they introduced themselves and explained what they were about to do.

6.6.1 Resignation

I asked Michael how he was. *"I'm fed up of my body"*, he replied. Yet when asked by a Registrar how his mood was, he replied *"not too bad",* although his voice was flat, his eyes averted. The extract below describes a review on ward round, by the locum consultant and registrar.

> *(Long discussion between Dr Basu and Dr Frank about medical situation - bilirubin, diabetic review, surgeons…Over 5 minutes)*
>
> *So far, they have been discussing him at the foot of his bed in a single room without introducing themselves. M watching them but not listening particularly attentively - more a gaze in their direction. Now they are looking at the bloods. The discussion goes deeper - Dr Basu turns to me and summarises the story:*

"he came in with infected pressure ulcers, there are no communications between the ulcer and rectum. He also has autoimune hepatitis and has a past history of PE[20] and AF[21]. He has had antibiotics and now needs K[22], LFT[23], RBC[24]. His INR[25] is on the slightly high side, he tells me. We need to keep an eye on it"

19 minutes after they first enter the room they finally talk to him

Dr Basu: "Good morning sir, how are you?"

Michael: "Not too bad"

Dr Basu to Dr Frank: "What was the outcome of the MDT?"

Dr Frank: "He was referred to the social worker"

Dr Basu to M: "How are things at home?"

Michael: "I don't live at home"

Dr Basu: "Where do you live?"

Michael: "England"

Dr Basu to Dr Frank: "Has anyone done MMT[26]?"

Dr Frank doesn't know. Dr Basu goes through the MMT, or mini-mental test. These include what year it is, how old he is, what month it is…and questions which I would find hard to answer if I had been in a room with no access to the outside world for several months, as in Michael's case.

Dr Basu: "How old are you?"

*Michael: "*38"

---

[20] *Pulmonary embolism*

[21] *Atrial fibrillation*

[22] *Potassium*

[23] *Liver function test*

[24] *Red blood count*

[25] *International normalised ratio (a measure of clotting capability of the blood)*

[26] *Mini Mental Test*

Dr Basu: "And looking at me, what job do you think I do?"

Michael: "Looking at you? Well, you're well-dressed. A good job, I imagine"

Dr Basu lifts the blanket to look at his feet. Listens to his chest. Does not ask permission. Does not ask about pain.

He leaves.

Afterwards, I ask Michael how he is: "Oh, 90% okay"

Me: "And what about the rest?"

Michael: (shrugs)

It was curious that the doctors elected to pursue assessment of cognitive function in this encounter. Michael had very little sight of daylight to orientate himself to diurnal or seasonal rhythms. He had lived alone with no access to newspapers or television to be aware of the current prime minister. Visitors to his room were frequent, and only that day included a surgeon, three nurses and a dietician. Some wore uniform, others did not. The question about the job that Dr Basu did may have felt something of a challenge in the light of this. Yet Dr Basu notes that Michael failed many of the MMT items. I reflect that he did not actually introduce himself when he had arrived, and furthermore that his name badge was on back-to-front. I wonder how difficult many of these questions would be for anyone in this setting, with all the comings and goings of strangers.

When asked how he was, Michael's most frequent response was to shrug. Although able to speak, Michael chooses the shrug as his means of communicating his resignation. The overall tone of his shrug was clear to observers yet the volition behind its expression was open to interpretation. A shrug conveys either that someone does not know the answer to something, or that they do not care. It conveys uncertainty, or that something is to be dismissed. So, either Michael did not know how the rest of him was faring on this day, indicating a state of disconnection from his body and his subjective sense of wellbeing, or he was communicating that he did not much care about how he was. Alternatively, the shrug might have been intended to challenge the

observer to push for more information; being subject to being ignored, and the resulting sense of invisibility, may have placed Michael in a position of wanting to hold on to his own information until he felt the listener was ready to listen.

Efforts made by nursing staff to improve his hygiene and appearance were well-intentioned but did not appear to ultimately have the desired effect. It was not his beard (or lack thereof) that made Michael suffer, but his ongoing pain, the indignity of having a wound that permanently leaked faecal matter, and the vulnerability and dependence of being confined to bed and surrounded by strangers. In the face of these obstacles it was hard to see how Michael could maintain his sense of self and adulthood. The clinical examinations of his wound not only caused physical pain but involved transgression of bodily boundaries. Examination of his wound and anus to establish whether the tissues between them had broken down was a profoundly degrading and painful intervention, and one which would normally be expected to cause vulnerability and anxiety. However, Michael's response was one of resignation. His statement that he was *"fed up of his own body"* implied that he saw his body as separate from himself. He had come to accept passively not only the shaving of his beard, but two painful (and probably futile) examinations of his pressure sore. Before he had come into hospital Michael had spent his time at home alone in bed, sometimes listening to the radio, but mostly sleeping. The only interruptions to his day came from visits from carers who – under pressure to achieve the required number of visits – often spent less than half an hour with him, washing and dressing him or preparing his food. On some visits, they would ask him whether he wanted something and he would wave them away. They would write in his notes *"declined cares today"* to cover themselves from potential litigation.

Michael's unkempt experience was often equated to a lack of wellbeing. In handover one morning, nurses were concerned that he had refused a shave. One staff nurse said *"we'll go back to him. Maybe Jasmine can work her magic - he'll feel better with a shave"*. The others nodded their agreement.

Later that day, suitably shaven, the nurses were pleased to report that Michael

is *“doing much better”*. I ask them what changed. *“We gave him a shave, he’s had a right good fettle”*. Another nurse nodded, *“he looked really unkempt.”* I peered around the door to say hello and see him. I hardly recognised him without his beard. His white, wispy hair was combed to one side. A cold cup of tea sat on the bed table in front of him, and he stared ahead, into space. He was the same person as before. I asked him how he is, and his shrug was the same.

6.7 Conclusion

This chapter has presented aspects of suffering relating to five of the participants: Vincent, Florence, Rita, Alfie and Michael. The extracts and discussion allude to the complexity of the suffering experiences of these patients. The accounts demonstrate numerous ways in which suffering was a shared human experience, with common and shared elements. Yet they also illustrate ways in which suffering was unique for each of these participants, and was a product of the situation in which they find themselves and their individual constitution. It was necessary to contextualise these accounts and this has taken the form of accounts of parallel conversations with staff, or environmental features. These contextual issues will be further examined in chapter 9 which attends to the issue of iatrogenesis – the potential for suffering to be caused or exacerbated by interactions, interventions or the environment.

Suffering took on a variety of forms for these participants that cannot easily be encapsulated in themes or categories. Particular events were selected from the field notes to examine facets of suffering that were felt to typify the experience of that participant. However, the accounts are by necessity both limited and limiting. Participants rarely conceptualised their experiences as suffering, but used a range of proxy terms or phrases to indicate suffering. True, these could also be conceptualised as distress, or dis-ease, or any number of synonyms that have been associated with suffering. However, the purpose of the chapter was not to drill down to an ‘essence’ of suffering but to present a series of stories that attest to the idiosyncratic and complex nature of suffering for these participants. The narratives in this chapter will be returned to in chapter 8 when

I undertake a theoretical analysis of suffering, locating the kinds of themes identified here within the broader context of the literature. This chapter will deal with issues such as alienation, loss and disconnection, drawing on a range of disciplinary perspectives to gain deeper understanding into the kinds of phenomena that contributed to the suffering experiences of these participants.

Chapter 7: White Knuckles, Tapping Spoons

7.1 Introduction

> *"Distress may be hidden, but it is never silent" (Regnard et al. 2007)*
>
> *"the materials required to understand suffering are of such a different order that we believe research approaches to it must deal directly with an experiential domain which heretofore, perhaps with the exception of the work of phenomenologists (which has its own problems) has been the grounds of art" (Kleinman and Kleinman, in Jackson 1989)*
>
> *"Suffering is at once everywhere and nowhere. It seeps through the cracks, through silences left in conversations, mundane or profound. It oozes through the pores of the ill and dying, grey and weighty. It sparks jaggedly, from the needles, syringe drivers, infusion pumps and shiny metal and plastic objects, the symbols of palliation" (extract, reflective diary, field notes)*

This chapter introduces the next group of participants – those who were unable to verbally articulate their experiences. Participants had been deemed to lack mental capacity for the purposes of participating in the study, as well as for many of the day-to-day decisions that therefore needed to be made on their behalf. For these participants, the ethnography is presented in a different way, and attention was paid to the embodied expression of suffering. As with chapter 6, use of theory is minimal and the chapter aims to present a set of patient narratives, each illustrative of a different facet of suffering. Because there was less verbal interaction, these narratives have been constructed using a combination of informal conversations with relatives and staff, and by using the principles of sensory ethnography outlined in chapter 3.

7.2 Ellen: Agitation

Ellen was unconscious when she was admitted to the ward. It was suspected that she had had a brain stem stroke or seizure. She had experienced seizures in the past, but usually recovered within a matter of hours. This time she had been unresponsive for over a day. She was 68 and also had stage IV heart failure and end-stage renal failure.[27]

> *I watch Ellen sleep. She seems peaceful, incongruous with the distress of her family around her. I do not think she is suffering. I'll observe her anyway as her journey will tell me lots about how end of life care is managed on the ward. She looks like she is dying. She is put into a side room, accompanied by her two daughters, Anne and Fiona. (Day 1 of admission)*

Over several days she drifted in and out of unconsciousness. When awake, she turned her head to identify the source of voices, but her eyes were glazed and did not focus and there was no response to the words of staff or her family who sat vigil by her bedside. Doctors were absorbed with task of trying to diagnose the cause of her unconsciousness. The question of whether it was a stroke or a seizure was significant because it impacts upon the likely reversibility of her condition, and hence her prognosis. During her first day of admission she underwent a battery of tests and scans which failed to draw any conclusions. That weekend Anne and Fiona, her daughters, became concerned that Ellen seemed to be becoming weaker, and demanded a review with regards to whether she might need a feeding tube. The regular dietician was not available so she was seen by the on-call, who was given the history from Ellen's daughters and the nurse. That day a nasogastric tube was sited, and a pump

---

[27] these two conditions often accompany one another, as the fluid accumulation resulting from a weakening circulatory system puts increasing pressure on the fragile vascular system of the kidneys. Management of end-stage heart failure often involves a difficult balance of medications that eventually cannot be adjusted any more. At this point, a palliative approach is generally thought to be appropriate (Gott et al. 2007).

set up by the bedside that drip fed the tan-coloured suspension of nutritional supplement directly into her stomach. When I returned to the ward on Monday Ellen seemed very different. Still mostly unconscious she had begun to open her eyes and make twitching movements in response to certain stimuli. Her daughters took this as a sign of recovery, and it affirmed their earlier assertions that she needed to have a feeding tube. However, when she opened her eyes, they usually rolled back in her head, and were unfocused. Her swelling had become much worse, particularly her legs which were shiny and taut. She made small retching sounds, and her neck occasionally twitched as though she were trying to lift her head. That evening, she began to vomit. Nurses were quick to attend to her, talking in low, reassuring tones as they wash her face and chest with warm water. Ellen seems oblivious, her eyes open momentarily then close again.

> *Ellen's daughters have gone. Her hands should be warm and dry but they are so swollen, they feel cold, like plastic. Her fingers are swollen, a sign of worsening heart failure as the fluid builds up in the interstitial spaces in her tissues. Her ring is tight on her wedding finger; she still wears it, even though Fiona told me she was widowed years ago. There are cracks that leak fluid. Despite myself I feel aversion to holding her hand but I continue to do so. I notice she is wearing silver nail varnish, but the varnish only goes halfway down the nails. It is growing out; a hearkening back to a brighter time, when she had a special event or was pampered by a loved one. Maybe a time when she wasn't thinking about hospitals or mortality. I realise my aversion to the texture and sensation of holding her cold hands has passed; it only took a moment to tune into the person who owned these hands, and it vanished. She became a person with a history, a family and a life (Field diary entry, Day 6 of admission)*

Over the next two days the frequency of her vomiting increased. She often tensed her muscles and tried to lean forward; sinews on her neck protruded with the effort. Her veins were swollen against her white throat. Her face -

smooth and unlined when admitted - became pinched, pale and furrowed. Although at times she seemed almost awake, she was unable to communicate with her family. When she heard the sound of Anne's voice she would frown, try to turn her head, but then her eyes would again roll back in their sockets and she would disappear back into her state of diminished awareness. Over time and after much discussion between the team and Ellen's family, the feeding tube was removed. The evening after the tube was removed, Ellen died.

> *Anne calls out from her room and a nurse rushes in; I follow. I see her tongue sticking out, it is dark. Her face swells and she makes a strange sound. Then she flops back against the pillow, exhales noisily. She does not breathe in again. Anne and Fiona are distraught; they lean over her, pulling at her nightgown, stroking her sweaty face. "*Mum*", they say, over and over again. "*Mum*". They are both crying. The nurse moves to stand beside them, a hand on their shoulders, in silence. I slowly back out of the room (Field entry, Day 9 of admission)*

Ellen's story is discussed in greater detail in chapter 8 where I suggest that although she was not suffering on admission to the hospital, a cascade of interventions led to a situation where she began to suffer, immediately prior to her death. Further, I argue that this was preventable, had she been accurately identified as approaching the end of life when first admitted to the ward. Ellen suffered the physical impact of a range of symptoms. It was not possible to ask her what was bothering her, whether she had any pain, or whether she felt anxious. The tension in her face at the effort and sensation of vomiting were the only external signs of distress. However, it was possible to intuit that there was suffering that accompanied the sense that she was unable to communicate with her daughters, and possibly fear at not knowing where she was when she awoke.

7.3 Sheila: "White Knuckles, Tapping Spoons"

Sheila was 82 and had had dementia for 6 years. Originally admitted from home with a urinary tract infection, she needed intravenous antibiotics and the infection was now resolved. She was in a side room because she had a positive MRSA screen on a previous hospital admission. She had been living at home but her family had been increasingly worried about safety. None of them lived nearby, but I spoke to her son and he said they were all hoping that she would soon be *"back on her feet, eating and drinking again"*. It was clear that she has deteriorated beyond the point where this was a realistic aim. She had been in hospital for over a month and most of that was in bed.

> *One morning, the consultant his rounds enters her room. He flicks through the notes, turns to the nurses, and asks: "*is there anything else we need to do for her?". *She is looking at him, frightened. The nurses shake her heads. "*She's social now*", they tell him.*

Despite being medically stable, her protracted recovery and prolonged bedrest meant that she no longer had the ability to function as she had prior to admission. It looked increasingly as though home would be impossible, but discharge to a care home was being hampered by disagreements between social services and health funders as to how much of her care requirements were 'social' and how much related to ongoing 'health' conditions. This was an important question, since the former would require a means-tested contribution from Sheila and her family, whilst the latter would be funded from within the health budget. However, the result of failing to settle on a plan meant that days had become weeks and then months.

Sometimes she was able to eat, although slowly and with much examination and manipulation of her food with her hands before it reached her mouth. On other days, she did not want to eat or drink, and shouted at staff to go away. When she needed help she would not press the call bell but would tap her cup on the edge of the bed table in various rhythms. At first, the plan was to move

her to a nearby hospital so she can be closer to her family, but over a period of several weeks she had become less amenable to rehabilitation according to the physiotherapists.

Sheila could often be heard calling out loudly "*what about me? What about me?"* when she as alone in the room. Alongside this cry, she would hit her cup or spoon against the bed table at ever increasing amplitude until someone would arrive at her doorway. However, more often than not, the person would simply admonish her and ask her to keep the noise down, before leaving again. When people entered her room, she responded in different ways depending on her mood. Sometimes one was met with a smile and greeting, but at other times that fearful wide-eyed look would dominate and she would shout "*no*" and throw things at the person. She was particularly fearful when staff attended to her personal hygiene needs and would often scream *"help me! Somebody help me!*" during bed baths. Staff would often try and defuse the situation through being jovial and friendly. Once, in the middle of a night shift when all was quiet on the ward, I heard her plaintively call out *"Nobody here. Here there is nobody"* and then begin to cry, sounding like a frightened child:

> *1:05 am: Sheila is calling out, frightened. In the room, in full light, two HCAs are trying to get her to put her top back on. She doesn't know what is happening. The staff are laughing, joking, attempting to be jovial but in the middle of the night in the glare of fluorescent strip lighting it seems peculiar, out of place, incongruous. Even a bit alarming. I sense her agitation and confusion. She is saying "*help me, help me*".*

It was not possible for an observer to accurately glean the meaning behind the action of casting aside her clothing. Staff discomfort was mitigated by the use of humour, to defuse the situation. For most people, the thought of accidentally exposing one's body to strangers is unsettling. Staff may well have been aware of this and have been using humour and light-heartedness to mitigate against the discomfort. Sheila was unable to enlighten us. So, it was made light of, negated, her clothes hurriedly replaced and her dignity temporarily restored.

The interpretive schemata for the healthcare support worker was that Sheila did not know what she was doing, that behaviour of people with dementia was often unfathomable, but she was also aware that it was important to maintain dignity and keep a positive attitude. These three perspectives combine in a bizarre way to render Sheila's behaviour laughable, and even though the healthcare support worker seemed to be aware that this was inappropriate, she was unsure of an alternative route that might have been taken.

I did not know whether Sheila, in an earlier time before dementia had taken hold, might have laughed at herself as she removed her clothing, or whether like many women of her generation the idea of immodest dress would have been abhorrent. Any assumption that I made could only ever be based on what limited knowledge I have of people I have met who were similar to Sheila. My assumption that she was shocked by the question was really my own shock, a condition respect for my elders, against a backdrop of deep embarrassment at seeing her unclothed in this way, and being in no position to leave the room without causing further distress.

7.3.1 Loneliness

When alone in the room, Sheila tapped her bed table. Sometimes she used her knuckles, but if a tool is within reach she would make use of it. A spoon, a cup, a bed pan. These objects were used to create sound to supplement her cries and screams of *"what about me?"*. There was a characteristic percussive rhythm to her tapping that cut through the background noise and could be heard as soon as one entered the ward.

Sheila's suffering was highly embodied. It was palpable in the expression on her face for much of the time, a combination of fear, confusion and sadness. Further, it was evident in the intensity of the screams and cries and sounds that she makes. These sounds were her means of interacting with the world, trying to call in some help and support and company to alleviate her loneliness and her fear. For Sheila, interaction with the outside world was a combination of primordial actions and socially conditioned behaviours, which sometimes conflict - as in the example where she takes off her hospital gown. The tension

between Sheila's instinct to remove her hospital gown, and her reaction on becoming aware that she had done so was illustrative of a tension between her need to express herself in a primordial, preconscious sense, and the sociocultural boundaries that were drawn around such behaviours and of which she still has awareness.

Even though Sheila could speak, and demonstrated insight and understanding in relation to many of the direct questions that she was asked, when she was alone in the room and needed attention her verbal communication was limited to repeatedly calling *"what about me? What about me?"* but louder than this was a banging that was much more likely to being the staff to her bedside. She would hit a spoon or other hard object against the metal of the bed cot sides or the plastic of the bed table rhythmically, getting louder and louder, until attention arrived. Sheila could be heard screaming and calling so often that many of the staff had learned to tune out the sound, as demonstrated by a failure to react or respond. They told me that even if you went in and addressed one particular thing, she would begin making noises again almost straight away. Even as they were explaining this, Sheila was wailing, thumping on her table. I realised that to an extent I had also learned to tune it out whenever in conversation with somebody else. It was necessary; the sound, intensity and words were distressing to hear.

Sheila was often unable to articulate her needs in a comprehensible form. She was at risk of having her suffering go unrecognised, so frequent were her expressions of distress. Staff found themselves forced to tune out her cries, with the undesirable consequence that Sheila became even more invisible. One of the contributing factors to her suffering seemed to be being ignored. Her verbal and behavioural agitation and calling for help intensified when staff ignored her or talked over her. This was compounded by the environmental situation; she was in a side room. Sometimes her calling was for a particular and identifiable physical need, as in the following example:

> *She has been crying out "*I want a wee*" for about 25 minutes.*
> *Some minutes pass; she is screaming now:* "I want a WEE! Oh

my god, oh my lord who do I have to ask?"

*The lunch trolley is being loaded up with trays of empty plates, nurses cluster around the pod. This is a time of busyness - nurses from the early shift have not finished but the late shift has just arrived and received handover. In this environment of noise and crowds, Sheila screams out again: "*Why not me? Why not me? Nobody wants to listen! I want a WEEEEEE!"

I'm exasperated. I have counted three people over this lunchtime period who have been in to tell Sheila that they are nurses and therefore cannot help her to have a wee.

There is a crash; Sheila has thrown her plate across the room.

Edith goes in: "What are you doing*?"*

*Sheila: "*I want a wee and nobody is here"

Edith:" I'll get a nurse, they'll come to you now"

At other times, it seemed that she just wanted human contact and her demand for attention was not followed through with any particular request:

Being washed by 2 nurses: Sheila tries to get involved in conversation with the staff. The nurses are leaning over her and washing her; they talk to each other about their summer shift patterns, holiday plans. Sheila's neck cranes forwards as she looks at one, and then the other. She smiles, her mouth forms the shape of a word that never emerges. The conversation has moved on to a different topic with great rapidity. Sheila looks confused. It becomes a formless sigh, then she rests her head back on the pillow as they begin to roll her on to her side to get access to check her bottom.

7.3.2 Disorientation

One day I went in to Sheila's room. She responded to me, said hello, then after

a few seconds she frowned and looks away, I felt she was about to say something but she's not quite sure what. I fed her porridge; she ate a few mouthfuls then seemed to forget what to do with it, played it around her mouth with her tongue, then spat it out again. A sip of coffee; the first went down, the second - she looked away (as if ashamed about dribbling) – came out of the corner of her mouth. Breakfast was finished:

*Me: "*I'm going to leave the room now, I'll come back and see you later"

*S: "*Oh no, don't do that, please. I'm frightened*"*

*Me: "*What of?"

*S: "*I don't know"

(Looks scared - keeps pointing at the printed sheets on the wall at the foot of her bed. Details about the local area, but in type too tiny for her to see anything other than black dots)

*Me: "*Shall I take those pictures away?"

*S: "*Ooh, yes please"

*Me: "*Do you want a different picture there?"

*S: "*I'm not bothered*"*

We have a brief conversation about holidays. I thought I heard her murmur "Malta" and when I asked her if she had ever been, her eyes brightened and she leant forwards.

"Oh yes, Malta..." *Her face was suddenly awake.*

*Me: "*What was it like there?"

*S: "*Ooh, lovely. All the ins and outs of it" *(eyes brighten, leans forwards)*

Later, I printed off a picture of Malta, and wrote in big script Malta'. I stuck it to her bedside locker. She looked at it blankly. I asked her if she has ever been to Malta. She didn't reply and looked confused. She looked out the window and frowned as though she didn't really know what I have just said. When she

looked back at the picture her gaze was blank, and she showed no sign that she recognises me - indeed she seemed fearful at finding a stranger in her room.

7.3.3 Indignity

Sheila was one of the patients identified as a *“double”,* meaning that two people were needed to *“do cares”.* The following reflective account, written after a morning spent in her room, gives a sense of what this experience was like for her.

> *I helped the healthcare assistants to wash Sheila. Sheila is a large woman, difficult to wash because she does not move her own body in any way that facilitates the task we are doing. She does move, but these movements are seemingly unrelated to her having a wash. She swats away an invisible object from in front of her eyes, she clasps the blanket and draws it up underneath her chin. When she does something with her body she appears disconcerted, ashamed almost.*
>
> *Sonia deftly and capably rolled Sheila this way and then that, streaking the warm wet flannel over invisible dirt. Porridge and soup have been dropped on to her hospital nightgown. She needed to be cleaned where she has been incontinent. A small red pressure sore on her sacrum needed a new dressing applying to protect it from excoriation.*
>
> *Flings off clothes then covers up her nakedness with her hands, fingernails long and grimy, eyes wide. The healthcare assistant is talking to me, chatting, telling me about what she thinks about her job, why she loves it, why she wouldn’t want to be a registered nurse - ”*you lose the patient contact*”, she says. Over the top of Sheila is - confused by the chattering*

She did not seem to know where she was and was easily frightened by sudden noises. Often, she undressed herself, throwing her nightgown out of the bed

and flinging back the blanket. Occasionally she realised she had done this, rapidly becoming mortified and frightened. At such times, she would clasp her arms across her chest to hide her body, her eyes would widen and she would glance around with jerky movements of her head and neck. When this happened, she would invariably notice at some point that she had done so. Then, she would become distressed and seek to cover up her modesty with her hands – which was difficult, as her breasts were large - or with the hospital blanket if it hadn't also fallen to the floor. Most often she would be found sitting upright in bed, completely naked, by whoever went into her room.

> *Sheila (takes off hospital gown and throws it to the floor)*
>
> *HCA: (smiling) "*Were you a stripper when you were younger?"
>
> *Sheila frowns: "*Dear god I most certainly was not*"*
>
> *(HCA grins at Student Nurse- they are amused but the question has caused distress - she doesn't know why she is doing it and looks alarmed when she discovers that her genitalia are exposed)*

Sheila's suffering was related to loneliness, fear and separation. She called for attention but then could not follow this through with a particular request. She was disorientated and confused which meant that even when someone was present she was unable to express her needs. Although she sometimes seemed less frightened with company than when alone, this situation could be reversed in certain interactions, such as if more than one member of staff was there, it was night time, or she was having her body washed or other intervention that appeared to compromise her dignity.

7.4 Dot: Worn Out and Weepy

Dot wept from the moment she arrived on the ward. She was an 88-year-old

woman with purple pyjamas, wild, tangled grey hair, and an enormous family. She was never alone. Within a day of her arrival on the ward, the walls of her room were covered in cards, scrawled pictures from grandchildren and great-grandchildren. Bunches of flowers and 'get well soon' printed balloons filled every spare space in the room. The lines on her face were deep but follow the shape of one who has laughed and smiled a lot. Her face when she arrived was not smiling; her eyes were crumpled closed and she cried continuously.

Dot had three cancers in three places in her body; her bowel, breast and endometrium. At a Calman-Hine meeting[28] prior to her admission it was decided that care would follow a 'palliative route' although staff differed in their understanding of what this means (the impact of this has been discussed further in chapter 5). Her wall was covered in birthday cards from yesterday, and more flowers. There was a picture from her great grand-daughter: *"goodbye nan"* it says. Mary, her daughter, told me that the consultant had told them all to say their goodbyes.

Her weeping had a unique sound; a weary, worn-out kind of crying. Sounds escaped through the open door into the ward corridor; chatter, the clink of cups of tea and coffee, an admonishment of a grandchild trying to pull on the bar of the ceiling hoist. This sound was placed against the backdrop of Dot's relentless weeping; a strange juxtaposition. Sometimes her crying took on a different pitch, increasing in intensity and conveying fear rather than exhaustion.

> *I introduced myself to Dot's family and explain the study. They nod their agreement, sign the Consultee Consent form. We talk about her crying, wondering out loud what is wrong. "*I think those net knickers are too tight", *her daughter volunteers. A cousin says,* "I think she needs the toilet*." "*She always does that", *her son tells me. Her granddaughter, a lively girl wearing a*

[28] *Regular multidisciplinary meetings are held place within UK hospitals in which patients recently diagnosed with cancer are discussed. These arose as a result of a report into cancer care* (Calman and Hine 1995)

*purple primary school uniform, corrects him: "*she's crying because she's sad*." He ruffles her hair. Another grandchild rummaged through her hospital notes at the foot of the bed.*

Even within Dot's family there were multiple interpretations as to the meaning of her weeping. I reflected that if her family could not agree on what was wrong, then the prospect of staff understanding Dot's suffering were even more remote:

Me to Dr Frank: "It's hard to know what is happening for her"

Dr Frank: "Yes"

Me: "Does she have dementia?"

Dr Frank: "No, but she has been like this since she came in, for a long time, even her last clinic letter said so"

me: "But if we were taking a palliative approach would the fact that she is crying continuously be something to attend to? would we think about that?"

Dr Frank: "Well the CT will show if she has brain mets, we have a strong justification for doing a CT[29]

me: "Do you think she is suffering?"

Dr Frank: (after a pause) "She is a scared lady"

As in many cases, the priority for the medical staff was trying to ascertain any underlying physical pathology that might be contributing to her current condition. Throughout the following interaction, Dot was unable to answer the question of whether she had pain or not. She looked frightened and gripped the bed sides. She wailed more loudly when strangers were in the room, clutching the blanket to her chin and staring ahead, wide-eyed.

The doctors arrive: (they do not introduce themselves)

---

[29] *Computerised tomography scan*

Dr Basu pulls up the blanket and touches her feet with his keys to check her sensations are normal. She cries out loudly, drawing her knees up to her chest. He puts his stethoscope on the part of her chest that is exposed by a gaping button in her nightgown - "Chest is fine", he says, but to his registrar rather than to her. She clenches her eyes closed and the pitch of her crying increases to a wail.

*Dr Basu: "*Just open your eyes please"

She does so

*Dr Basu: "*Both pupils are fine"

…

to D: "Would you like some oxygen through a tube?"

Dot: "NO!"

Dr Basu "You'll feel better"

Dot: (cries loudly)

Dot was often talked about as though she was not there, both by healthcare professionals and her family. Although she did have cognitive problems, there were times when I saw her respond to simple questions, but most were answered with increased weeping and distress. This gave the impression that trying to involve her has caused, or worsened, her distress. Yet she was also clearly distressed by the conversations that take place around her of which she was not invited to be a part.

The sound of her cries was tuned out through necessity (in much the same way as Sheila's calls for help) by those involved in the conversations. The weeping eventually took up a continuous place in the background. Seeing her relatives not reacting to the sound seemed to make it easier to ignore; they were not concerned and did not think it was unusual behaviour for her, so staff soon adopted this position as well:

Dr Basu: "Good morning. How are you today?G

No answer

Dr Basu: 'Can you hold out your arms for me?" (her crying gets louder. She sounds frightened)

Dr Frank: "This sound is normal for her"

However, when a new member of staff encountered her it was common for the staff member to appear disconcerted and alarmed - as illustrated in the following example. On first meeting Dot, Claire – a student nurse – had looked alarmed at the sound of her crying – she had glanced at her mentor behind her as she entered the room as if to ask whether she should do anything. Her mentor was called away and Claire entered the room alone. She seemed uncomfortable; she talked rapidly over the top of the sound of Dot's weeping:

Claire telling Dot a story about fluffy socks. She is smiling while she talks. I'm not sure Dot is understanding the story but it seems to settle her momentarily.

Now Claire is talking about the Yorkshire Show. Too much. She speaks quickly, a little nervously, smiling brightly (too brightly) all the time. It is incongruous against the backdrop of Dot's crying. She cries louder. Tracey wraps Dot's hands in her own – Dot stares down at her hand, recoils visibly.

"ooh your hands are lovely and warm. I bet you don't get cold in winter…my dad's are like yours, he radiates heat. Crikey you are warm, I might just end up sitting next to you all day" keeps on chatting, smiling …

Eventually Claire seems to realise the incongruity and quietens down. She looks at me (approval?) Doesn't look at all comfortable with the silence.

Suddenly:

Dot: "My feet are cold!"

Claire: "Shall I get you some socks?" (Jumps up quickly, eager to do something)

Although Dot was still eating, drinking and swallowing her medicines, it was decided to prepare for future deterioration and the probability that she would become unable to tolerate oral medications. Standard practice in such instances was to site a 'butterfly'[30] in the tissue (usually the arm or stomach) to enable repeated pain-free administration of injections:

> *Helen (staff nurse): "I want to put a tiny tube in your tummy because I don't want to keep having to give you injections. Would that be okay?"*
>
> *D: "I don't know"*
>
> *H: "It would feel like a little scratch when it goes in but after that it's all sorted. Would you like me to show it to you?…she shows and describes it, slowly, gently….do you think that would be okay?"*
>
> *D: "Yes"*
>
> *H: "And when I am doing it I will talk to you so you know when I am going to do it. Do you want Claire to hold your hand?"*
>
> *(holds her hand up, Claire gratefully takes it)*
>
> *H and Claire have brief conversation about how long to rub with alcohol wipe for to ensure it is sterile.*
>
> *H: "Is that okay? It feels a little bit cold but not too bad"*
>
> *She washes her hands, opens a wound kit on the bed, quickly and skilfully places the butterfly*
>
> *H:"Aall done, that's sorted now. Let's get some mouth care swabs. Bring me a kidney tray and some Vaseline"*
>
> *At the sound of these words, Dot's eyes open and she cries out in alarm. She is trying to say something but it does not sound like formed words, more like a low-level moan.*
>
> *(I find myself thinking about how alarming Helen's words had*

[30] subcutaneous cannula

sounded but actually how benign they were for someone who understood the objects she was referring to - a kidney tray is just named after its shape, and the Vaseline is for her chapped lips….)

The following morning Dot was awake when I arrived, lying on her side facing the door. She was not crying today, at all. I go into her room. During handover, they mention 'anticipatories'. Despite staff being in broad agreement that she was for a palliative approach, there was still resistance to implementing the kinds of medical interventions that were associated with this, such as anticipatory drugs:

Dr Basu: "Citalopram or midazolam? I would like to hang on before we write up anticipatories, because I saw her yesterday"

Dr Frank: "But just in case?"

Dr Frank is writing up the anticipatories. He doesn't seem to know why or to be able to articulate his rationale for each of the drugs. He writes a range for the haloperidol, 0.5-3mg. I ask him how the nurses would know when to give the lower end of the range and when to go for the higher end. He says, "if the nausea is not actual vomiting go for lower, then if there is a lot of really bad vomiting go for the higher amount" ….

Long discussions about pain…Dr Frank wants to cross off the zomorph if he is writing up diamorphine. But I tell him that if she is already on a regular analgesic it is almost certain that she has continuous pain - to manage this with pens only is to invite the pain. And we know that pain is at least part of her distress because of how settled she was after having oramorph in the night. Eventually he agrees. I have stepped outside researcher role again.

I spent a long time the following day sitting beside her. That day there were no visitors until the late afternoon and she was asleep most of the time. I found out she had two lots of morphine overnight. She was not crying anymore. Outside, the telephone rang; it was her daughter. I heard the nurse saying, *"she had a bit*

of an unsettled night and the nurses gave her some medicine and it has settled, she's been quite comfy ever since." I wondered why it took such a long time to get analgesia for here, and I also wonder (paradoxically) if she was now over-sedated. I reflect on the complexities of interpreting her weeping. Was her suffering really as simple as unmanaged pain all along?

7.5 Bert: The Rain Came and Thunder and Lightening

Bert was 94 years old. He was the main carer for his wife Elsie who has dementia, they lived at home prior to admission. He had been feeling on edge, trapped and anxious. Constantly worried about Elsie's safety and his own ability to look after her long-term, this hospital admission was (in his daughter's words) the *"thing he had been dreading"*. His wife had been taken into emergency respite care. He was admitted because of chest pain and dizziness. On admission, he said that felt as though he were dying. He had been diagnosed with a 'vasovagal episode' largely ascribed to the heat of those summer weeks. Alongside this issue he had developed septic arthritis and cellulitis in his hand. His physical condition had deteriorated. The infection had led, quite suddenly, to an episode of acute delirium. During this episode, he lost capacity to consent to the study which was obtained from his daughter as consulted. When I first saw him, he was still in the throes of his delirium but I went to see him again a few days later when he was able to recall much of the content of that frightening episode, helped by his daughter. Bert retained clear and frightening memories of the experience. He referred several times to the image of his mother, daughter and son sitting upright in chairs but being dead. The realisation that Elsie, his wife, had reached the stage where she would most likely need someone to care for her day and night had precipitated a crisis of anxiety when he developed the infection. Bert had been finding it increasingly difficult to care for Elsie although according to Kate found it hard to admit this, as he had made himself a promise that he would not let her ever go into a home. Kate felt that his infection had been caused by a lack of sleep and ongoing stress.

Bert continued to refer to the memories of his delirium, almost as though he was trying to make sense of them. The following excerpt is taken from a

conversation with Sally, the mental health liaison nurse:

> *B: "It were getting darker and darker and I came across two women and they pushed me into bed, I thought I were dying, I thought my son and daughter were dead. All dead"*
>
> *Daughter: "It's been hard, dad"*
>
> *B: "I can't look after her no more" (daughter glances at Sally and mouths "mum")*
>
> *Sally: "It might be that you don't have to look after her any more"*
>
> *B: "Why am I here?"*
>
> *Sally: "Because you've burned yourself out. She probably should have been in a home years ago but you persevered"*
>
> *B: "Well I've thought so for a while now but I didn't want to say anything. I can't go back to that flat" [suddenly, as though he's just remembered home] "but there's my money and my telly and things" [leans back in chair] "If I could just sit somewhere and watch the telly and do my crossword I'd be happy"*
>
> *Daughter: "He's deaf, he's blind, he's knackered - aren't you, dad?"*

For Bert, the delirium precipitated a crisis in which he realised that he was becoming unable to care for his wife any longer. Over the following days However, he was full of worries, about what would happen to her, where she would go, and how he would be able to contact her. As the memories of the delirium receded he was faced with the new reality that his whole social world was about to change. His wife would need to go into a care home, and he would be left at home, alone.

7.6 Lilian: They've Taken My Eyes

I first met Lilian lying on a trolley in the corridor when I arrived for a morning

shift. She was admitted overnight, an emergency, through A&E. The healthcare assistants were in the bay getting her bed ready. She had been 'parked' here so the nurses could keep an eye on her, and so that the noises she was making did not disturb the sleep of the other patients in the bay. She was grasping the hospital blanket tightly and pulling it up to her chin. She wore a pink nightgown that was rucked up over thin, mottled legs. Her black slippers looked too big. There was a cannula in her left arm and she glanced at it repeatedly, frightened.

The ward was noisy, as was usual at 7.30 in the morning. The lights were all on, and up and down the corridor were the sounds of patients waking, water running, sheets being snapped open, pillows plumped, commode wheels rattling, the macerator in the sluice grinding. Lilian looked fearful, and her head darted to follow the source of different sounds.

The nurses told me she has come in from the Medical Assessment Unit. She had a diagnosis of dementia but had developed a delirium which they were presuming has resulted from pneumonia. For this, she was having intravenous antibiotics twice a day. I looked back at her and see she was crying. "*My eyes"*, she moaned. *"They've taken my eyes."* The nurses were concerned about her degree of agitation - *"she's a big falls risk"*, they told me.

Lilian was unable to tell me about what was happening to her. I tried to piece things together by observing her. Once she was moved into the shared bay, I took a seat in the opposite corner to watch and listen. It was clear that she was distressed by strangers, by noise, and by different kinds of stimuli. I did not want to add to her distress. Every time there was a sound, Lilian jumps. Hannah, a staff nurse, has noticed how sensitive she is*: "I ruffled her hair in a friendly way and she nearly shat herself, literally…but…she is so scared. The doctors won't prescribe anything for her hallucinations, we need to talk to them today."*

The following day, there were concerns that Lilian's voice sounds different. Her throat sounds constricted and there was a whistling as she breathes. She could not seem to swallow food or drink; she choked, spluttered, and spat it out. Her agitated shouting was now more of a croak. It was decided that she needs to be

reviewed by the Ear, Nose and Throat consultant, who decided that an endoscopy was indicated. This involved using a long, flexible tube with a camera at the end to examine her throat. The following extract from the field notes relates the event:

Around the bed: ENT consultant, Kirsty (staff nurse), Dr Basu (geriatric consultant).

ENT: “In what way is her swallowing worse than before?”

K: “She can't eat or drink at all”

ENT: “They've asked me to scope her. Will she let me?”

K: “Well she's had haloperidol an hour ago”

ENT: “Okay I'll get my scope”

Her son Ben arrives. He watches for a minute; Lilian looks like she is swatting away flies. Her eyes seem focused on something in the distance, and her forehead is furrowed with worry. She makes a low, growling noise.

Son: “How is she?”

K: “Hallucinating quite a lot, she would shout I’m sure, if she had a voice to shout with. It's like something's blocked”

K (to Lilian): “This doctor has come because of your sore throat”

L: (no answer, grips blankets, looks terrified - her eyes are darting from one person to the next, then at her son, then at the doctor)

K: “The doctor needs to look at your throat. Don't be scared. I'll hold your hand. This is going to go up your nose”

son: “Her nose?”

L: (cries, flings her head from side to side)

son: “She can't hear what you're saying, that's the trouble. I don't know where her hearing aid is”

ENT: “I don't think she will tolerate this”

Suddenly L is smiling and looking at the doctor. She grabs both of his wrists and tries to pull him down to her and laughs. ”Hello", she says.

ENT: “Let's try again”

(She struggles. They hold her head still but she is strong in her fear. They give up, discuss the option of using midazolam to sedate her for the procedure. This is rejected. ENT suggests a barium swallow)

K: “But she can barely swallow”

ENT: “I'll discuss with my colleagues. Her chart says she has had some intake so maybe we just leave it”

So, she didn't have her hearing aid battery in, or her glasses on, plus an acute delirium. I am trying to imagine how that experience must have felt for her.

7.7 Roland: He’s in That Graveyard There

Roland - although able to talk - had quite severe cognitive impairment. His suffering was not told literally but was possible to explore the richness of the symbols embedded in the stories he told (graveyards, brothers, being lost, good shoes) and the questions he asked.

Roland was a tall, thin man, distinguished despite dressing gown and pyjamas, his glasses hung on a cord around his neck. He did not like it in the shared bay; the man in the bed opposite him called out, day and night, and disturbed his sleep. The nurses had had to intervene on more than one occasion to prevent a fight. So, Roland spent much of his time walking the corridors of the ward. He greeted those he met, usually with a smile, but sometimes with agitation, irritability or anger. One day, he stopped me as I was walking past:

“Will you come into my room and tell me what you see out of the

window so I know which way to go?" I walk with him.

As we navigate the corridor, he tells me he was looking for his friend. We sit down together on the plastic covered seating halfway down the corridor and he continues:

"He's not in this graveyard here, he's in that graveyard there. We've been friends for 51 years and now in five years' time I'll be dead, I shouldn't be surprised. All I want is some cash and half an hour to go and visit him on my birthday. I haven't gone home because there's a lunatic in my room swearing and shouting. Look, I haven't even got shoes on."

Three nurses walk past and he stops talking to follow them with his eyes.

"All three of them said they'd help but none of them did. They don't have the power. Fifty-one years. I want to be able to go down the road and feel gracious, feel free. I'm not expecting fees, I just want to be able to say "hello John, how are you settling down? I know your wife died, but…" we grew up together for 90 years."

It sounds like you were a bit like brothers, I tell him.

"We were, yes we were. I fail to understand why people can't say "oh all we're doing is taking this bloke by the hand and talking for a couple of minutes and then pulling back…"

His head turns and he looks at my shirt. "it's no good talking to you, you've no authority to help me."

More nurses walk past and he tries to get their attention. They are avoiding eye contact and speeding up slightly as they go past. We sit together for around twenty minutes.

"I'm just looking to see him say 'by Timothy, I'm glad to see you', that's all.

He stands up and leaves, walks across to the Clean Utility Room

(this is where the medications are dispensed). Hannah is coming out through the door as he approaches.

"This is a sterile room, sweetheart, and only staff can come in. Have you got one of these?" (she shows him her NHS lanyard). He stares. "Why don't you go and find your shoes?" she suggests.

He turns and walks away.

He was told that if he did not possess a staff badge, then entry to the room was forbidden. He never came to understand what was inside the room. He was refused entry at the point of expressing curiosity and his curiosity remained undiminished. Through this action, he was excluded from the population of people permitted access, and left with little or no agency. Roland was only too aware of the limitations that power impose on his agency. Further he was aware somehow that I lack the power to help him in his endeavour. It was unclear whether this was because of my gender, my lack of official hospital identification, or the absence of a stethoscope around my shoulders or a nurses' distinctive uniform.

On another occasion, Roland was searching for a shoe shop:

"They need to be good and strong, enough to get me far", he tells me. "Do you know anywhere that sells them?". I tell him I don't, and we compare my shoes and his bare feet, agreeing that neither would be suitable for a particularly long walk. He walks off again, still searching. He is frowning, he looks perpetually lost. Despite his restlessness and ceaseless walking, he is tired; his arms and legs shake when he stops, but he seems too agitated to stand still for long. He doesn't want to wear his slippers and rejects staff offers to help him put them on.

Roland sometimes seemed aware that he was in hospital but at other times looks bemused at the prospect of wearing slippers. He was firmly of the mind that walking boots would help him to continue on his journey, even though he was not entirely certain of his destination. He was rarely in his bed; when not

walking, he often sat on the row of plastic-covered seating halfway down the ward. Sometimes he said he is waiting to be met by a friend, other times he asked if the bus as due soon. Sometimes, however, he just sat and stared into the space in front of him, a space occupied only by three identical doors on the opposite side of the ward. All of them state 'Staff Only'.

Nurse: "Get out of Sheila's room, Roland"

R: "I'm looking for John. Have you seen him?"

Nurse: "No, I haven't"

He appears at the door and catches my eye.

R: "Have you seen John? He was just on the other side of the building when I lost him…"

7.7.1 Depersonalisation

Embedded in Roland's suffering was a sense of lost identity. He was continuously searching and dealing with his nagging sense that someone or something needs to be found. References to objects and people from the outside world seem to help him in his endeavour to orientate himself to this present peculiar environment. Without reference to John, or the bus, or good shoes Roland sensed his identity to be at risk. He understood himself in relation to others but most of his interactions on the ward were functional or involved him receiving instruction or admonishment from a staff member.

R is following Lucy, a healthcare assistant, down the corridor:

R: "Can you show me?"

L: "Right, just take a seat for me because we are going to be busy with dinners soon and the nurses with meds"

In the hospital Roland had very little social capital. Surrounded by rooms he was forbidden to enter and spending his nights in a room full of strangers who were all wearing the same standard-issue hospital pyjamas, Roland's social capital had been eroded. Social capital was sustained by social networks; therefore, these kinds of depersonalising events eroded Roland's sense of self

and added to his suffering.

For some reason John was a recurrent topic of conversation in Roland's talk. It was significant that Roland was searching for his friend in a graveyard. A graveyard is not a neutral location. Many questions remained unanswered about John's identity. Perhaps he was an old friend from work or army days, perhaps he was still alive or maybe he had died many years ago. Perhaps he was a lover, hidden for many years through Roland's marriage and after his widowhood.

Roland did not know the reason he did not want to wear slippers. One possibility was that slippers are often associated with homeliness and comfort, and with bedtime. Roland was unsettled by this as he clearly does not feel at home. He was looking for robust shoes in which he could leave the ward and walk to his destination. It was impossible to know where he would walk to if suitably shod in sturdy boots and if permitted to leave the hospital gates. Despite being rebutted several times a day, Roland was unceasing in his efforts to find his friend.

7.7.2 Afterthought…

I include the extract below to illustrate how simple and effective interventions that promote personhood could be.

> *I arrive one afternoon on the ward and see Roland walking, arm in arm, with Jasmine, a healthcare assistant. They are chatting, but I don't hear what they are talking about. He seems relaxed, his stride is more purposeful than the shuffle I remember. As I get nearer, I hear:*
>
> *R: "If there is another bed in this hospital I'll bite their hand off"*
>
> *J: "I've put your chair outside your room so you don't have to go in there with him. Come on, let's go back together"*

Throughout the rest of that shift, Roland seemed relaxed, affable and calm.

7.8 Conclusion

This chapter has addressed the topic of suffering by describing examples where participants could not directly describe to me their experiences. Suffering in these narratives required a degree of interpretation, and this was done using sensory ethnography. The focus was on the nature of suffering, and on placing this within its broader context. The stories of Sheila, Ellen, Bert, Lilian and Roland added to the picture painted by the last chapter, in that they support the premise that suffering could be identified and described even when little or no verbal interaction was had with the sufferer. These aspects of suffering were less tangible; they defied robust explanation or theorising, and there was no way to validate the interpretations with the participants. Interpretation of the behaviour and action observed was subjective, but where possible I have presented as much data to render the excerpts sufficiently 'thick' to permit the reader a degree of freedom of interpretation.

The stories of suffering in this chapter attest to feelings of loss, fear, alienation and loneliness. They overlapped to some degree with the accounts in the previous chapter but also manifest distinct features that accompany the particular predicaments in which the participants find themselves. Again, the word suffering was not used directly, but the broad range of physical, social, psychological and spiritual distress that was represented was encapsulated under this broader term.

In the next chapter I examine the phenomenon of suffering in theoretical terms. Led by the findings of Chapters 6 and 7 and the various facets of suffering described, I examine how these facets were supported or challenged by the existing literature from a broad range of disciplinary perspectives including sociology, philosophy, nursing, medicine and humanities. The experiences of the participants in this and the preceding chapter will be once again visited but

the focus will be on placing them in a broader theoretical context rather than just describing their stories.

Section 3: Analysis, Discussion and Conclusion

Chapter 8: Suffering: A Reflective Analysis

“Suffering is in us, like a pit in fruit, and all around us, like air, like life. Yet, we, and I think that I can speak for all of us when I say we, we are incapable of defining suffering, of dealing with it, of speaking about it” (Katz and Johnson 2006. p631)

“Oh, help me, please doctor, I'm damaged
There's a pain where there once was a heart
It's sleepin’, it's a beatin'
Can't ya please tear it out, and preserve it
Right there in that jar?” - Mick Jagger

*suffer early 13c., "to undergo, endure" (pain, death, punishment, judgment, grief), from Anglo-Fr. suffrir, from O.Fr. sufrir, from V.L. *sufferire, variant of L. sufferre "to bear, undergo, endure, carry or put under," from sub "up, under" + ferre "to carry" (see infer). Replaced O.E. þolian, þrowian. Meaning "to tolerate, allow" is recorded from late 13c.* (Oxford University Dictionary Online no date)

8.1 Introduction

The aim of this chapter is twofold. Firstly, I aim to investigate how theoretical perspectives on suffering can illuminate or deepen understanding of participant experiences. Secondly, I consider the reverse; whether and how the experiences of participants can inform or develop existing theoretical perspectives. The participant narratives in the previous chapters identified multiple facets or themes of suffering. I argue that the participant narratives attest to the nuanced nature of suffering and consider the resonance of these

stories with what is known about suffering, according to the literature. In order to achieve this, I examine what the literature says in relation to each theme. Because it is such a vast topic, I adopted a pragmatic approach to the literature, searching clinical, philosophical and sociological perspectives, considering how each theme interfaces with existing literature. I propose that a missing element of healthcare practice lies in really understanding the complexity and variety of suffering experiences, and that improving compassionate care requires that suffering is foregrounded in research and education. To aid the reader in undertsnadinfg identifying the main themes for exploration, an overview of the patient narratives and their corresponding themes has been presented in Appendix 5.

8.2 Suffering: a theoretical background

> *“When I think about suffering I sort of imagine a spider diagram, with all sorts of things linked to it, like pain and sickness and loneliness...it’s just too big a thing to think about as itself. We talk more in terms of problems, because here, there’s a person that can deal with each issue - so if its social, there’s a social worker, if it’s pain, there’s the doctor, and things" (Rebecca, Staff Nurse)*
>
> *“If illness did not involve suffering then it would present only a technical, instrumental problem” (Frank 2001, p355)*

In section 8.2 I provide a brief overview of some of the theoretical perspectives relating to suffering in general terms within the healthcare literature. In section to I examine literature relating more specifically to themes of suffering drawn from the patient narratives.

In the medical and nursing literature, suffering is often referred to as a proxy for having a diagnosis of something (for example, *'suffering from dementia*', *'suffering from comorbidities'*) rather than viewed as a phenomenon in itself. Suffering is a shared human experience (Duffy 1992) that influences wellbeing. Kahn and Steeves (1986) posit that suffering is best understood as it relates to a perceived threat to some aspect of oneself.

A key theoretical perspective on suffering in healthcare comes from the work of Cassell. A physician in New York, he joined the Task Force on Dying at the Hastings Centre in 1971, which was to profoundly influence his personal philosophy of medicine and direct the next few decades of scholarship. Particularly interested in the moral issues that surround dying, he wrote extensively on the nature of suffering. He considered that suffering can be defined operationally as a *"sense of impending personal disintegration"* (Cassell 1991, p25). Central to his thesis is the contention that failure to address the person as well as the body leads to failure in addressing the real issues at the heart of human suffering in clinical practice.

Van Hooft, a philosopher, challenged Cassell's efforts to distinguish suffering from pain, arguing that this equates to a form of dualism. Instead, he proposes that suffering is the manifestation of thwarted 'teleos'. It can manifest in many ways, independent of consciousness; a person unable to speak or otherwise communicate their suffering can nonetheless suffer. In other words, humans strive towards the achievement of various goals (biological, social and so on), and suffering presents itself as an interception and interruption of this process (Van Hooft 1998). Based upon this idea, he claims that it is possible to frame all suffering within the four Aristotelian aspects of living: the biological, the appetitive, the deliberative, and the contemplative and it is only the person who is suffering who is in a position to evaluate their suffering. Furthermore, it is beyond the role of physicians to attend to a person's spiritual suffering. This, for Van Hooft, is a matter for society.

Edwards (2003) challenges Van Hooft's approach, suggesting that frustrated teleos is neither necessary nor sufficient for suffering. Indeed, he rejects philosophical and scientific attempts to capture the nature of suffering. Instead he suggests we turn to language: we can know far more about suffering through exploring how it is used as a word in everyday language. To be useful suffering should remain an intuitive concept, and avoid being captured in the 'net of science'. In an edited volume on social suffering, Kleinman *et al.* (1997) observe that suffering occupies a problematic place in cultures that place faith in biomedicine. The mechanistic conceptualisation of the body permits diseased organs to be replaced, or faulty systems to be supported by advanced medical

technology. One of the book's key arguments is that although phenomenological and existential aspects of suffering are important, the experience of suffering is socially situated and shaped historically and politically. As such, experiences of suffering are both individual and collective. In a later paper, Kleinman argued for a difference in how we view disease and illness, where the former refers to a state of disrupted physiology, and the latter is socially and culturally defined. It is in the sociocultural realm that the differing paradigms regarding the nature of suffering become articulated. He observed that *"culture fills the space between the immediate embodiment of sickness as physiological process and its mediated (therefore meaning-laden) experience as a human phenomenon"* (1988, p27). Cultural differences between the patient and healthcare professional can affect not only whether and how suffering is recognised but also what is even considered to be suffering. The social and cultural nature of chronic illness, suffering and death has also been addressed by authors such as Corbin (1998) and Charmaz (1999; Charmaz and Paterniti 1999).

8.3 Facets of Suffering

Section 8.2 provided a brief overview of some key theories of suffering. I now turn to seven specific themes that have been derived from the patient narratives in Chapters 6 and 7:

1. Vulnerability and frailty
2. Disempowerment and choicelessness
3. Uncertainty
4. Alienation
5. Loss of Time
6. Loss of Meaning
7. Loss of Dignity

This is not a comprehensive list. The narratives attest to a far more nuanced and complex description of suffering. The purpose of this chapter is to develop these seven themes to explore the potential utility of narratives in the development of theory around contemporary understanding of suffering.

8.3.1 Vulnerability and Frailty

All informants demonstrated a level of vulnerability. Vulnerability has been defined as the *"outcome of complex interactions of discrete risks, namely of being exposed to a threat, of a threat materializing, and of lacking the defences or resources to deal with a threat"* (Schröder-Butterfill and Marianti 2006, p1). All people at some time will go through the experience of being dependent upon another human. The need for care is universal, although it manifests differently at different times of the life cycle. It may be perceived that for older people there is a shift in this reciprocity and the requirement for care returns to being unidirectional. To a certain extent, vulnerability is an inevitable part of the experience of older people admitted to hospital. There is bound to be some illness or debility-related need or other that cannot be met in their home environment that has necessitated admission in the first place. In some circumstances, vulnerability is exacerbated through well-intentioned efforts to remove responsibility and burden from patients, which can lead to deconditioning and loss of agency. Further, perceptions of patient vulnerability can become a kind of self-fulfilling prophecy whereby there is a gradual surrender of control to the health and social care providers, ultimately leading to the difficult position where the patient is no longer able to exert independent actions in some areas. Irurita's (1999) grounded theory study of 23 patients identified vulnerability to be the most common shared experience of hospitalised patients; her study population included a broad range of ages and she identified that the self-perceived risk of vulnerability appeared to be greater in the older patients in her sample. The reasons for this are several; the impact of ageism and negative attitudes from staff was felt to influence subjective feelings of vulnerability. Further, periods of hospitalisation were likely to be longer, and the existence of comorbidities that compounded dependence were more common.

Sarvimäki and Stenbock-Hult (2014) interviewed 14 people over 70 about what they understood vulnerability to mean. Participants described feeling progressively more exposed to the environment as they aged. Thwarted attempts to grow and develop were seen as contributing to vulnerability.

Further, there was a close link between perceptions of dignity and perceptions of vulnerability. Participants were predominantly female. Furthermore, they lived in either their own homes or supported accommodation, and none were cognitively impaired. Sarvimaki offers useful insights into perceptions of vulnerability in relatively well older people. Interestingly, the author had earlier conducted a study that explored nurses' perceptions of vulnerability (Stenbock-Hult and Sarvimaki 2011). Nurses considered vulnerability as an essential human attribute and a means of connecting with patients. There were differences in perception of what constituted vulnerability in an older patient and what constituted personal vulnerability as a nurse working with this client group. Vulnerability could alternately be seen as either a resource or a burden, depending on individual capacity to learn from the experience.

Out of familiar surroundings, and subject to different routines, patients are vulnerable to feeling unsettled, exposed and at risk. This can be compounded by the physical and emotional burden of illness, which may add a further layer of unfamiliarity to their experience. It is not uncommon for patients to express feelings of vulnerability. These may manifest as anxiety, anger or other forms of resistance. Alternatively, vulnerability may be expressed through a withdrawal and resignation from active attempts to engage in the world. Vincent strongly resisted the intimation that he was vulnerable; each time an assessment of his 'needs' was made he expressed fear at the rapidly changing future, and ambivalence about the nature of the care he would require, alongside a grudging realisation that his vulnerability was increasingly seen as a fact that was not just contingent on his current state of ill health and hospitalisation but a far more wide-reaching diagnosis of his future world.

Garcia-Dia (2013) notes that when strategies to understand vulnerability through professionalised lenses are adopted the result tends to be one of disempowerment, whereas when vulnerability is framed from the person's perspective there can be a sense in which it is rendered bearable and at times can even become a source of strength. One important objection to the notion of vulnerability is that viewing older people as inherently vulnerable risks worsening the disadvantage of older people in society. It can only be a useful

concept if it is applied judiciously to refer to those who are suffering directly because of their vulnerability. It is less useful when applied as a blanket term to all older people who are hospitalised with life-limiting conditions. Rita is an interesting example of a participant who - whilst disempowered and dealing with the impact of uncertainty in relation to her prognosis - did not perceive herself as vulnerable in the slightest. Her resilience appeared to be related to her self-perceived ability to retain those things that she valued; interest in other people, her mental faculties. Her stories revealed that these were the things that she considered synonymous with deterioration and giving up, and by comparing herself firstly to her husband, and then to the others on her bay who had cognitive impairment, she distanced herself from such things and retained a sense of strength.

Although vulnerability is a common human experience across the lifespan, attitudes towards it from those in caregiving roles are far from consistent. It is common in our society to observe that babies - who are dependent, incontinent and unable to make decisions for themselves - evoke caring and protective responses almost universally. Conversely, the same dependence in relation to bodily functions in an older person is frequently met with disgust and aversion (Lawton 1998; Goldenberg *et al.* 2001; Holmes, Perron and O'Byrne 2006; Simpson 2012). One of the contributory factors to a feeling of vulnerability voiced by participants in Sarvimäki's 2014 study was the loss of dignity that arose out of changes in bodily functions. Loss of dignity and vulnerability are therefore closely related.

Vulnerability or Frailty?

Patients can perceive themselves as vulnerable, or they can be perceived as vulnerable by others. Recent developments in gerontology have seen the evolution of the concept of frailty which has been proposed as an alternative way of conceptualising the specific kind of vulnerability observed in older people. However, it has been argued that frailty is a more medicalised notion and focuses on objective measures of risk, rather than subjectively felt vulnerability (Clegg *et al.* 2013; Chen, Mao and Leng 2014). It has been suggested that vulnerability is one factor of frailty (Markle-Reid and Browne

2003) but more recently this notion was superseded by the argument that the converse is true; frailty gives rise to vulnerability on account of the increased risk that frail people will experience multiple morbidities, hospital admissions and life-limiting illnesses (Rockwood *et al.* 2005). Brocklehurst and Laurenson (2008) consider that vulnerability in older people incorporates not only the physical, social, psychological and spiritual dimensions but can also have impact through exclusion from research, lack of representativeness in policy, and additional issues around intersectionality, such as gender, sexuality and ethnicity.

Van der Meide *et al.* (2015) suggest that viewing vulnerability as frailty alone ignores the important role of the hospital environment in creating situations in which patients are vulnerable. That is, they may be less vulnerable in their own familiar world but finding oneself in a new and unfamiliar environment engenders an additional type of vulnerability. A crucial difference between frailty and vulnerability is that frailty denotes a multidimensional loss of function that is largely framed in terms of physical function, cognition, energy and health (Rockwood *et al.* 2005) yet the definitions do not include a subjective element that relates to the impact of such limitations on the individual (which will doubtless be influenced by numerous buffering and aggravating factors such as personal resilience, support and so on). As such, it is an objective notion. Therefore, vulnerability is a preferable term as it applies both to how an individual is seen in their world in terms of risk (professional-centred view), and to how the individual might see themselves and the kinds of things that might prompt concerns for them.

Disempowerment

Disempowerment is closely related both to vulnerability and choicelessness. For Bourdieu disempowerment is a product of unequal capital - notably social capital - within the field of practice (Wacquant 2013; Pellandini-Simányi 2014). Bourdieu's notion of habitus is a fluid one; individuals can adapt and change their orientation towards themselves and their surroundings in response to interactions with others in the field, and as a result their comparative levels of capital can change with time. Rita's habitus prior to admission comprised social

and cultural capital that were enacted through roles such as matriarch of her family and so on. Once admitted to hospital, she entered and became a part of an unfamiliar field. She was ascribed certain characteristics by virtue of her status as a patient, some of which she resisted vehemently.

In the encounters with the medical team, Rita perceived herself to be excluded from important information pertaining to herself and her body. These instances drew out a contrast between her common-sense understanding of people (as subjects of some interest) and the medical conceptualisation of the person (the disease or condition for which hospitalisation was required). Rita's interpretation of events referred to her present moment situation and offered a window to her past and her broader habitus. Further, she repeatedly alluded that she was well aware of the progressive loss of her power in this new and unfamiliar hospital environment. Social categories such as age, race and disability create and perpetuate levels of disadvantage, and in some people the existence of multiple categories means that the impact of such disadvantage is potentiated through intersectionality. An example of this was brought out in Rita's story because she was treated as though she has dementia, even though she did not. Withholding medical information was not seen as particularly unusual by the team, but for Rita it was a source of suffering.

Withholding medical information from patients, particularly in life-limiting illness where prognosis is uncertain, is not uncommon (Lamont and Christakis 2001; Visser, Deliens and Houttekier 2014) despite increasing emphasis on shared decision-making in healthcare policy (Department of Health 2012). Multiple factors may influence this behaviour, including perceived socioeconomic status of the patient (Légaré *et al.* 2008) confidence of the healthcare professional (Heyland *et al.* 2009; Peters *et al.* 2013) and difficulties talking about dying. Information may be withheld because it is perceived that the patient will find it intellectually or emotionally challenging to process or understand the information. For example, in current guidance around 'Do Not Attempt Cardiopulmonary Resuscitation' orders staff were instructed to discuss with the patient unless discussion is likely to cause physical or psychological harm. This guidance is somewhat circular; clinical judgement as to the patients' likelihood to be harmed psychologically relies upon the establishment of rapport and

intersubjective awareness. The less of a connection is made, the more likely it is that it will be judged that the patient cannot deal with the information. Capacity to understand information can be easily misconstrued based on a minimal response or intermittent confusion, and 'psychological harm' is open to multiple interpretations. To a lesser extent this applies to discussions about illness more generally. In excluding Rita from such discussions there was a cumulative disempowering effect that was potentiated. Each example of exclusion served to strengthen Rita's antipathy towards the team, and consequently to affect the manner of her communication with them. This then strengthened the team's view that Rita was not able to participate meaningfully in discussions about her care.

Some evidence appears to contradict what was observed in Rita's case; Strull *et al.* (1984) suggested that doctors were far more likely to involve patients in decisions relating to their care if the patient is perceived as having an active interest, although there is admittedly a difference between active, positive interest and active, adversarial involvement. The situation here may have been different not least because a health service over a quarter of a century later was subject to a great many new and different pressures influencing the doctor's perception of a patients desired level of involvement. More recent research observing older people's involvement in planning gives cause for ongoing concern (Ekdahl *et al.* 2012) as staff were preoccupied with patient discharge, and perceptions were that patients were too tired, ill or cognitively impaired to involve in efficient and productive discussions.

This example illuminates what is potentially a very common way in which doctors discuss patient care for people without capacity. Even with varying levels of cognitive capacity people may notice when someone is talking about them. They may hear themselves mentioned by name, or may notice a group of people looking at them. This can be a disempowering act in itself given that it excludes and objectifies the person. Maben *et al.* (2012) conducted a study of hospitalised older people to explore patient and staff experiences of care, and identified that around a third of participants felt that the doctors and nurses talked about them as though they were not there. Given that the study sample size (n=26) was taken from an initial sample of 111, there is some limitation in

the degree to which this can be generalised. Further, although there was little information on the condition or morbidity of the patients, it was likely that they had capacity in order to be able to complete the survey. This does not therefore reflect the experiences of those without capacity who may well constitute a large proportion of the 'parcels' to which Maben refers.

By way of contrast to Rita's experience was that of Sheila, who was disempowered in multiple ways but was unable to articulate how this impacted her. Another contrasting example was Vincent, whose response to disempowerment was to further withdraw and become uncommunicative. In his current circumstances, he has little agency. His experiences of grief, chronic illness, social isolation and long-term depression have created an aggregate experience where his coping mechanisms were few, and these were placed against a backdrop of an existing chronic illness, increasing difficulty in caring for himself, and the threat and uncertainty of a potential additional life-limiting illness with all the incumbent decisions to be made. He draws some strength or solace through reflecting on his past. For Vincent, there was no purpose looking to the future. His only sense of agency and control was through either defiance in the face of interventions, or of taking his freedom into his own hands by trying to get out of bed and go to smoke a cigar. But without achievable goals there seemed to Vincent little purpose to the exercise of autonomous decision-making. Even making goals relating to clinical treatment relies on at the very least a wish to live, and in Vincent’s case it was not clear whether he did indeed desire this. Both Vincent and Alfie made use of silence to resist the disempowering effects of hospitalisation. Latimer’s (1999) ethnography of hospitalised older people identified the active use of silence as a strategy for patients to resist being categorised in an undesirable way – for example, as having problems that were primarily 'social' rather than 'medical' (which was viewed to confer a lower status on them during their hospital stay and to invite judgements from staff regarding the extent to which they deserved to receive hospital care.

8.3.2 Choicelessness

A further aspect to disempowerment was the perceived absence of choice. This was where participants may appear to have been involved in exercising their

autonomy but in fact their choices were either limited or dictated by the requirements of the institution and care team. Being deprived of choice has been found to lead to disempowerment and subsequent feelings of vulnerability and exposure (Bridges *et al.* 2010). Vincent's multiple discussions with the discharge team and social workers were examples of this. His real choice would be to go home and be left alone, to smoke cigars unhindered, to use the stairs shakily, and to live out a potentially shortened life in the way he wished. Over time and multiple discussions various factors were introduced that undermined these original choices, mostly focused around safety and resources. Eventually Vincent reached a state of choicelessness where he deferred all decision-making responsibility to others: *"I don't want to make the decision. I want someone else to do that. Just MAKE the decision what to do next."*

Ideas about choice are closely linked to theory on autonomy, whereby autonomy within healthcare has been variously defined as self-determination, freedom, independence, liberty of choice and action, individual control of decision-making and other activity, and human agency free of outside intervention and interference (Collopy 1988; McWilliam *et al.* 1994). Where choices were apparently presented, as in the number of carer visits per day, these were not the kinds of choices that might have actually empowered self-determination. The rhetoric of choice was performing a function in relation to the public-facing role of the ward and the hospital, but was not acted out in practice, primarily because the options that would represent the full range of what patients might wish for were unavailable. For example, the social worker could not offer a time when home carers would visit which Vincent understood to mean that once home he would have to just lie in bed until they arrived, but furthermore he did not want to be asleep when strangers arrived at his home so he would have to set an alarm clock. There may be a wait between waking and the carer visit, potentially of several hours, during which time he would have to remain in bed and not have breakfast. Framed in this way, it no longer seemed like an enabling choice.

Habitus transformation is often referred to in a positive sense, to explain phenomena such as high student professional achievement despite oppressive

social conditions (Lehmann 2013). However, transformation can also occur in the reverse direction. Habitus dictates many of the choices that a person is able to make, but the existence of external obstacles can impede this. Thus, there was an internal framework that Vincent referred to that limits his options, but this as reinforced by the repeated feedback he received from those involved in his care, strengthening his sense of choicelessness.

8.3.3 Uncertainty

> *"When a new disability arrives, I look about to see if death has come, and I call quietly, 'Death, is that you?'" (Scott-Maxwell 1979, in Nanton et al. 2016)*
>
> *“Will you tell me how I am”? (Hilda, patient participant to doctor)*

A common theme relating to suffering was uncertainty. Uncertainty has been defined as *“confusion about the meaning of the environmental configuration”* (Lazarus and Folkman 1984). It is a cognitive state created when the person cannot adequately structure or categorize an event because of the lack of sufficient cues. Uncertainty occurs in a situation in which the decision maker is unable to assign definite value to objects or events and/or is unable to predict outcomes accurately (Mishel 1984, 1999). A concept analysis by McCormick (2002) argues that uncertainty is a neutral cognitive state and should not be confused with its emotional sequelae. However, other scholars have illustrated close connections between the state of uncertainty, and emotional states of suffering such as hopelessness (Morse and Penrod 1999; Van der Meide *et al.* 2015) and it is conceptually closely linked with vulnerability, discussed earlier in this chapter.

The clinical literature on uncertainty largely relates to how this impacts on professionals, and locates it in the domain of prognostication, diagnosis and care needs assessments (Fox 1980; Meier *et al.* 2001; Rich 2015). The fact that professionals may fail to communicate uncertainty to patients can exacerbate patients' perspectives that it is only them who feel unsure about things whilst all around them the clinical team have access to some authoritative insight into

things as they are (Broom *et al.* 2015). I have already discussed the issue of uncertainty in relation to clinical practice and how this impacts on multiprofessional working, but the impact of uncertainty on patients is profound and extends beyond the realms of diagnosis and prognosis. Patients face uncertainty around immediate issues - how the next few hours might unfold, who might come to see them, whether a new medicine will make them feel better, and so on (Crunkilton and Rubins 2009). They also face medium and longer term uncertainty that relate to treatment, discharge from hospital, and future care and decline, including friendships, retaining control over care and dependence (Black 2011).

Suffering and uncertainty are inextricably linked. Cassell (1991, 1992) observed that accepting illness or deterioration requires a surrender of firmly held ideas in relation to self. This liminal state is associated with uncertainty as a person needs to redefine many aspects of themselves in order to integrate their current suffering into their perception of who they are and who they might be (Karlsson *et al.* 2014) The experience of uncertainty can also be linked with existential doubt, particularly for those patients who had a sense that they were approaching the end of their lives (Arndt *et al.* 2005; Arndt and Vess 2008; Greenberg, Solomon and Arndt 2008; Yalom 2010). Vincent's reflection on being *"just dust"* poignantly communicates this sense, and needs to be read alongside his other concerns regarding the temporal aspects of suffering. The anthropological notion of *liminality* - the state of being 'betwixt and between' (Gennep 1960 /2004) is conceptually useful here as severe illness and dying constitute an important rite of passage, even if this is not framed as such within the biomedical model. The sense of being an outsider and of not belonging in this environment can contribute to feelings of uncertainty (Digby *et al.* 2017). From a Bourdieusian perspective, patients have not developed a 'feel for the game' and the field remains a confusing place, where it was not clear what stakes were being played for, or what strategies might be utilised in order to gain greater familiarity of the field. It was akin to learning a new language, but with the added complexity of having to believe in the goals of the field in order to engage fully in the game; this was the *doxa*, or the level of adherence between field and habitus. Those patients who resisted care were

communicating that they did not share the *doxa* with the staff on the field. Whilst this position allows resistance, it also seems to perpetuate the uncertainty with which patients were able to successfully navigate the demands of the field.

The literature does not address the experience of uncertainty in dementia as experienced by the person with dementia. Again, it emphasises the experience of caring and planning for a person with dementia rather than examining the experience of the person with dementia (Dening *et al.* 2012; Pinkert *et al.* 2017). In some ways, though, all of the experiences of the participants with cognitive impairment convey a sense of how uncertainty contributed to their suffering. Lilian's disorientation in response to her various experiences were exaggerated when there was a new person, or a confusing situation. Bert's experiences during his delirious episode all spoke to a sense in which he feared the uncertainty of his future. Roland's search for good shoes seemed at times to be a metaphor for taking him from this liminal state to a place of familiarity and certainty.

8.3.4 Alienation

Alienation is recognised as an important aspect of suffering within the nursing and medical literature (Younger 1995; Best *et al.* 2015). The concept itself finds roots in both the existential philosophical traditions, and within sociology, although the latter largely refers to the alienation of workers within capitalist structures and societies (Seeman 1959; Seeman and Evans 1962). Alienation is a core facet of Illich's thesis (1975) displaying important similarities between his position and that of Sartre. Conversion of the human body into commodity is a causative factor in the alienation experienced by humans at the hands of medicine. Furthermore, alienation was situational rather than an inherent trait of either Florence or Vincent. It was an emergent product of their current context, which in itself was an aggregate of being away from their usual worlds, unwell and in hospital. This theme will be further elaborated in the next chapter where I consider the phenomenon of iatrogenic suffering. For the purposes of the present analysis I identify three modes of alienation: alienation from self, from others, and from society.

Alienation from self

Alienation from one's lifeworld is an aspect of suffering. However, it is also possible to be alienated from oneself, particularly from one's body. As well as the confusing array of new routines and practices that people were expected to conform to, there was an additional layer of alienation that arose through the experiences of illness and ageing. Illness led to changes in bodily functions, impaired level of independence, and symptoms such as pain and fatigue. Scheper-Hughes notes that the body can be viewed from three perspectives: as a phenomenally experienced body-self, as a social body, and as a 'body politic', or an *"artefact of social and political control"* (Scheper-Hughes and Lock 1987, p6). Sveneaus (2011) speaks of 'otherness' which is to be understood as a *"foreignness that permeates the ill life when the lived body takes on alien qualities."* Drawing on Heidegger's notion of being-in-the-world, Sveneaus proposes that illness creates an unhomelike sense of existence. This is positioned in opposition to health, which he conceptualises as a state of transparent being-in-the-world in which the lived body is the point of access to ways of being in one's environment. Illness is constructed as an alienation from a person's past and future selves and as an intrusion into one's life that requires a retelling of both past and future narratives. Illness forces re-evaluation of one's relationship with one's body. Sartre famously noted that it is only in a state of illness that one becomes properly aware of one's physical, lived-in body as distinct from one's imagined body, and that a discrepancy between these two develops in the state of illness. Certainly, when illness becomes severe and the body no longer performs as one wishes it to perform, the body can become difficult to control or predict. Havi Carel (2013) describes her experience of being diagnosed with a terminal lung condition as the moment when these two 'bodies' separated and her biological body became at odds with her phenomenological body. This disconnection between the self and the body has also been considered in terms of ageing; the *'mask of ageing'* concealing the unseen inner self, and people feel that they are different to the body observed in the mirror, or which fails to perform in its expected ways (Featherstone *et al.* 1991).

Of course, despite the pervasiveness of Cartesian dualist thought regarding the separate existence of mind and body, to be alienated from one's body is really to be alienated from oneself. As embodied beings, we experience our bodies as an indivisible part of our whole perceptual field, which includes our thoughts and emotions. Merleau Ponty's notions about perception can help to illuminate why separation from one's body is equivalent to separation from oneself (Merleau-Ponty 1962; Carman 1999). According to Merleau Ponty, when we perceive something we do not do this through our separate individual senses and then aggregate them into a whole, whereupon we interpret the sense data to give us information about what it is we have perceived. Rather, perception takes place as a whole, through a process he equates to Gestalt. Thus, alienation from self, and alienation from body, were really two sides of the same experience.

The body, once familiar, has become strange and liable to do unexpected and unwelcome things. Michael described himself as being *"fed up with his body"* illustrating the degree of alienation that he felt from his own physicality. It was not performing as it had done in his past. A combination of his immobility and the wound that continued to deteriorate, belied a body that had betrayed him. Sacks refers to this when he had the experience of a severe leg injury and found he could not move the affected limb. He described the experience of looking at this part of his body and having a sense that it did not belong to him, and that it was actually a 'thing' that was once his leg (Sacks 1984, p53). The pain from Florence's leg ulcers had become chronic, lasting for several weeks. She expressed bodily distress at the anticipation of dressing changes but also would visibly avert her eyes from the sight of her legs, even when bandaged, as for example when she was being transferred from her bed to her chair. It was as if she did not wish to be reminded that her legs were a part of her.

The experience of pain is an aversive bodily sensation. People with pain may distance themselves from the source of the pain as a means of self-preservation (Scarry 1985; Sofaer *et al.* 2005). This can lead to a form of alienation from the body or the offending body part (Scarry 1985; Charmaz 1999). These psychological strategies are known to become more commonplace as pain becomes chronic (as opposed to acute) (Hughes 2008) and this is one reason that chronic pain requires a multidimensional approach to

management. Furthermore, Florence's body was regularly objectified through clinical examinations. Her body belonged both to her, and to the medical establishment. The part of it that was known to the establishment was alien to her. She was unfamiliar with the particular bacteria that were colonising her leg ulcers, and did not know that the stage of inflammation of her wounds were causing the release of a cocktail of inflammatory mediators that sensitised her nerve endings to alert her brain to the presence of damaged tissues. She only had her directly experienced body and her directly perceived pain.

Cicely Saunders conceptualisation of 'total pain' argued for the integration of psychological, social and spiritual aspects into the care of people in pain (Saunders 2006; Middleton-Green 2008; Clark 2014). Any pain associated with life-limiting illness should be viewed as 'total pain' as the various elements would always be present in different degrees, in different forms, and to different intensities. Saunders was keen to broaden ideas of caring for the dying to include attention to these other facets of existence, and her philosophy has been highly influential in the development of the current World Health Organisation's definition of palliative care in which suffering (not pain) is the focus of care (WHO 2010). The original impetus for this work was said to be a patient who - trying to describe how he felt - told her he had a sense that *"all of me is wrong"* (Saunders 1964, in Clark 2014). Despite Saunders' work and extensive subsequent scholarship within palliative care, the majority of medical references to pain and suffering consider pain to be a biophysical phenomenon, or at least to be physiologically reducible (Chapman and Gavrin 1993; Ruijs *et al.* 2013).

Alienation from one's body can also come about through the experience of being a recipient of care, particularly when the effects of illness were bringing about some bodily dysfunction. Both the impact of having one's body attended to by others, and the feelings that arise in response to its failings, can lead to suffering. When Vincent was offered a wash, he asked if he could be left smelly a bit longer. He would rather be left smelly than surrender his independence to the indignity of being washed by a student. By making this request he was seeking to retain his independence, and was also alluding to what he had intuited from the nonverbal communication of staff - that he was in need of a

wash in order to smell better. The purpose of the wash was not entirely for his benefit but was also for a general all-round sense of cleanliness that would give the staff satisfaction and help them to avoid the unpleasant smells that made the body work aspect of their role less palatable.

Common to the experiences of Michael, Vincent and Sheila was a sense in which aspects of life that had previously been private had been rendered public. Depending on others for bodily care is a significant transition to make, and whilst for many this is a temporary state that accompanies illness and hospitalisation, for these three participants the transition was not to be reversible. They had all surrendered a level of autonomy and control of their own bodies to the hands of others, of strangers. This was accompanied by suffering. Twigg's research into bathing, the body and community care reveals thoughts of older people associated with advancing age, increasing dependence, and changing relationships with the body. One of her participants ("Mrs Ostrovoski") observed that something happens to one's relationship with one's body on admission to hospital in which the only way to survive was to distance oneself:

> *"when you go to hospital…and you are there and you have twenty students….you lie naked and you are becoming example of the things…and twenty people touch you and you just close your mind and you say yourself it doesn't matter, it doesn't matter, it doesn't matter…you are really a subject. You are not a person" (Twigg 2000, p55)*

By describing his experiences following a diagnosis of lymphadenopathy, a recurrence of his earlier cancer, Frank portrays suffering in the absence of physical symptoms. He contrasts his suffering during the time of investigations with another experience of physical pain, where he injured his shoulder reversibly. He described this as *"pain with more annoyance than suffering"* (Frank 2002, p354). Similarly, Alland's autobiographical account relates how following admission to a psychiatric hospital she found herself:

"suddenly struck by poverty of speech it, to someone whose life has evolved around conversation, to be plunged into deep water when you're unable to swim - the sense of drowning, the loss of solid ground, terrifying. The only noise is the babble of water spluttering over you as you sink deeper and deeper beyond a place where sound has meaning…a place where sound merely echoed the hollow empty void of life as I perceived it - nothing but an illusion of connection in an alien, dissociated space" (Alland 2004, p168)

Alienation from others

Alienation from others is different to loneliness. It refers to being alone without the desire for others, whereas loneliness conveys a sense of longing for others yet being alone. As social animals, it was perhaps inevitable that a move from a familiar world into the strange terrain of the hospital ward would be accompanied by disorientation and distress. Contact with those who were most familiar was restricted to visiting times, and the social roles of both the patient and the visitor were markedly transformed during these times. Even where the visitor previously had a caring role, this was largely supplanted by the ritual of visiting, sitting by the bedside and making conversation and speaking to staff about the current state of things. Very rarely were visitors observed to be involved in the act of caring, whether or not they might have wanted to be involved in this way.

Solely because of having an advanced and life-threatening illness, all the participants were marked out as different from the world of healthy people outside the ward walls, and who constitute the healthcare team. The participants rarely formed a cohesive community with one another; they were diagnosed with different conditions, they were often isolated by being in different rooms from one another. Although I did witness on one occasion two female patients singing songs together across the bay, the majority of interactions between patients were non-existent, ambivalent or overtly negative - as with Roland and the man in his bay who, he claimed, was disturbing his sleep.

Even when in company of others it is possible to feel loneliness and alienation. The experience of illness could exaggerate this existential aspect of suffering (Sand and Strang 2006; Ettema *et al* 2010). The loss of one's social networks and roles are part of this experience. Younger (1995) considers alienation in the context of ways in which suffering influences a person's sense of connectedness with their community. Her argument centres on alienation from others. Importantly she discusses suffering and relationality and notes that suffering sometimes destroys the ability to communicate the experience to another human, and that this in itself intensifies the degree of alienation from others. Whether through the absence of a satisfactory language of suffering, or the intensity of the experience, the difficulty in conveying such subjective distress to others proved problematic to the sufferer. Alienation as such was not an absence of connection but a sense of negative connectedness as a process that unfolds through ongoing relationship in a particular context. It incorporates but is not confined to ideas about meaninglessness, powerlessness and lacking belonging.

Alienation from society

Vincent (on home): "it's a distant place to me now"

The hospital ward was an unfamiliar place for patients. The environment and the routine were standardised around the needs of the ill and it was incumbent on patients, as transient residents, to adapt to this as far as they were able. Feeling distanced from one's usual surroundings and lifestyle was commonplace. The alienating effects of hospital admission have been addressed by numerous scholars (Goffman 1957; Seeman and Evans 1962) and there are several first-hand accounts of this (see for example Frank 2002; Carel 2013; Scully 2013). Oliver Sacks describes the process of hospital admission for a surgical procedure thus:

> *"One's own clothes are replaced by an anonymous white nightgown, one's wrist is clasped by an identification bracelet with a number. One becomes subject to institutional rules and regulations. One is no longer a free agent; one no longer has*

rights; one is no longer in the world-at-large" (Sacks 1984, p182)

Foucault describes how the new 'social order' within the hospital requires that patients are segregated from society, so regardless of who that person might have been outside the hospital walls there is a process of homogenisation where the characteristics of being a patient must be adopted and the person effectively disappears, subsumed into the broader medical goal of surveillance and treatment (Foucault and Sheridan 1973; Jewson 1976) Patients become persons out of place and their usual sources of social, cultural, economic and symbolic capital are denied to them as a result. Rita's indignant responses to a lack of involvement in decision-making, as well as Roland's anger at being told to go and sit down, were just two examples of how this might manifest behaviourally. Both referred to situations outside their current circumstances in which their personhood was being asserted - Rita through a description of her family, and Roland through reflecting on his friendship with John.

8.3.5 Loss of Time

Pain - has an Element of Blank - It cannot recollect
When it began - or if there were A time when it was not -

It has not future - but itself
Its Infinite realms contain
Its Past - enlightened to perceive New Periods - of Pain
(Dickinson 1960)

Roland did not explicitly refer to feeling bored, but there was a repetitive nature to his searching behaviour. Often, such behaviour in people with dementia is assumed to be a part of the condition. However, work in Dementia Care Mapping which distinguishes between behaviours associated with wellbeing and behaviours associated with feeling ill-at-ease makes a distinction between associated activities and there is increasing recognition of the impact of boredom on the behaviour (Brooker 2005; Perrin 1997). Vincent and Alfie

referred more explicitly to their subjective sense of time and to the impact this had on their wellbeing. Alfie described himself as *"just watching sitting the clocks go around and round. And being moved about like a piece of meat"*. This not only hinted at the sense of boredom, but also revealed how for Alfie this was linked to a sense of purposelessness.

Alfie did not want to be in hospital and rejected attempts to investigate and treat his pathology; his clock-watching was a behaviour associated with boredom, with waiting to go home, and with frustration about time wasted. Vincent, in contrast, awaiting key decisions about treatment, discharge and social care package, watched the clock in anxious anticipation. When his waiting was interrupted by a member of staff entering his room, there was often momentary hope. The concurrent monotony and anxiety was interrupted by the promise of action or activity. More often than not, these visits were simple assessments, reviews or repeats of earlier visits, and this led to an accumulated sense of frustration which served to amplify his ambivalence towards staff. Further, Vincent was patently aware that his health was deteriorating. The paradox of running out of time, whilst still experiencing boredom and anxiety about the future, was not lost on him.

Phenomenological studies of lived experience of suffering at the end of life portray the temporal aspects of suffering (Charmaz 1999; 2008). Suffering relates to a 'self' which is understood by selected aspects of the past, is experienced in the present, yet relates to a future threat.

Another important temporal aspect of suffering was boredom; an indicator that a person was not actively engaged in the world around them. The majority of scholarly work in the area has been in the field of psychoanalytic psychology, although more recently there has been burgeoning interest within occupational therapy (Martin 2009). It has been theoretically linked with reduced pleasure (anhedonia), depression and aggression (Greenson 1951). Fenichel (1934) was the first to address boredom from a psychoanalytical perspective, noting that the bored person is in a state of tension where their objects and aims are repressed. He considered it to be a heterogeneous phenomenon, pointing to

the fact that some people become agitated when bored, and others become withdrawn and silent. Greenson defines boredom as "*self-administered deprivation"* that leads to a "*state of dissatisfaction and a disinclination to action*" (Greenson 1951, p7). Leahy *et al.* (2012) undertook a survey of boredom in 71 inpatients across three specialist palliative care units and found a prevalence rate of 79%. Boredom is known to have a significant psychological impact on wellbeing. The subjective perception of time is dependent on one's emotional state; it appears to slow down when one is bored or apprehensive, and to speed up when one is excited or joyful. Slowed down perception of time can exacerbate subjective perception of symptoms such as pain, which is one justification for using distraction techniques to help manage such symptoms non-pharmacologically.

William James proposed that subjective time may be perceived of as shorter or longer than chronological time; when things are going badly, suffering increases, and subjective time is perceived as being longer than chronological time (James 1898, in Stanley 2012). This notion was taken up by Bayes *et al.* (1997) in their development of a tool purported to assess suffering based on how long time seems to the sufferer. Passik *et al.* (2003) suggest that boredom possesses enough unique qualities to distinguish it from depression. Their sample of 100 people with cancer asked about boredom-specific factors including having a sense of time passing slowly. However, the assumption that suffering makes time appear longer might be confounded when prognosis is poor; time may seem more precious and the rapidity of its passing may itself be the source of suffering. Being admitted to hospital causes a disruption in the usual flow of time, where the past becomes hazy, a source of nostalgia, an impossible goal to recreate, and the future becomes an opaque expanse of unknown outcomes - at the core of which for nearly all of the participants was the possibility of death; closer now, since the most recent admission and deterioration of health. The overlap between the studies by Passik and Bayes demonstrates the conceptual difficulties in restricting subjective perception of time to a particular phenomenon (whether boredom or suffering, or both), but nevertheless there appears to be sufficient evidence that temporal aspects can contribute to subjective suffering.

8.3.6 Loss of meaning

> *"the prisoner who has lost faith in the future, his future was doomed. With his loss of belief in the future he also lost his spiritual hold; he let himself decline and become subject to mental and physical decay. Usually this happened quite suddenly in the form of a crisis, the symptoms of which were familiar to the experienced camp inmate. We all feared this moment. Not for ourselves, which would have been pointless, but for our friends. Usually it began with the prisoner refusing one morning to get dressed and wash or to go out on to the parade grounds. No entreaties, no blows, no threats had any effect. He just lay there hardly moving. If this crisis was brought about by an illness he refused to be taken to the sick bay or to do anything to help himself. He simply gave up. There he remained, lying in his own excreta, and nothing bothered him any more." (Frankl 1964, p82)*

A theme in Michael's story was that his life has lost meaning and that he has lost purpose. His request about being put *"on the scrapheap"* was intended to be light-hearted but there was a very poignant sense of loss in this statement. The concept of social death is associated with these kinds of suffering experiences and echoes Cassell's argument that suffering is essentially related to a loss of meaning. Opportunities for meaning-making were restricted when one is in hospital. The normal social activities that provide meaning were replaced by hospital routines, restricted visiting times, and agendas set by illness, symptoms and professionals rather than by free choices. Although it is outside the remit of this thesis, there is a strong association between loss of meaning and requests for assisted dying (Hendry *et al.* 2013; Ruijs *et al.* 2013). This suggests that loss of meaning is a highly significant aspect of suffering for people with life-limiting illness. Because the concept of personhood is intimately associated with what gives a person's life meaning, diminished personhood poses an existential threat. Depersonalisation as a facet of suffering can be compounded by illness, hospital admission and the state of uncertainty that life-

limiting illnesses bring about.

Patients may suffer when they perceive that their personhood has been reduced to their illness. The practice of medicine can inadvertently have a depersonalising effect on those it seeks to cure. Kleinman (1988) uses Weber's notion of the 'iron cage[31]' to critique the preoccupation of health professionals with physical illness and pain, and a technologically narrow vision of treatment. A loss of personhood means a disruption to one's biography and history, as well as one's usual social and cultural sense of place. If - as Frankl suggests - we are not destroyed by suffering but by suffering without meaning, then it is important to consider the implications of what it means to lose this sense of meaning. For Cassell, a person is

> *"an embodied, purposeful, thinking, feeling, emotional, reflective, relational, human individual always in action, responsive to meaning, and whose life in all spheres points both outward and inward. Virtually all of a person's actions—volitional, habitual, instinctual, or automatic—are based on meanings. Persons live at all times in a context of ever present relationships in which a variable degree of trust is necessary both in others and in the self" (Cassell 2010, p50)*

Personhood refers to those elements that make an individual who they are; personhood can exist in the absence of being able to make autonomous decisions. It relates to a sense of self, and is biographically based and unique. Further, it is intersubjective. Zeiler (2014) draws upon Laitenan's theory of personhood to draw distinctions between monadic cognition-orientated ideas of personhood (which equate more closely to the notion of autonomy discussed above) and dyadic conceptions, in which the person is an individual but one that participates in various practices that situate her/him such that he/she becomes viewed as a person by another. This notion is echoed by Kitwood, who argued

[31] a metaphor for increasing rationalisation of everyday life. Weber's iron cage is inflexible and dehumanising, a manifestation of the bureaucracy that characterises modernity.

that personhood is a standing bestowed on one person by another (Baldwin and Capstick 2007).

Kitwood and Bredin (1992) conceptualise personhood as having both subjective and intersubjective elements. Central to this is a view of personhood as being a social rather than an individual phenomenon. As such, interactions can either promote, conserve or diminish personhood. Within Kitwood's framework, dementia is seen as having neurological elements that can lift function, but also psychological and social elements that impact on wellbeing. One example here was the way in which Sheila avidly tried to follow the conversation that the two care assistants were having about their holiday while they were giving her a bed bath. Her eyes moved from one to the other and several times she seemed about to say something, only to break eye contact and look away, seeming to be trying to find the right word. Ultimately, she did not participate in the conversation at all; it all took place over her. This interaction could be seen through Kitwood's framework as an example of malignant social psychology. Kitwood and Bredin allude to behaviours common in people with dementia that are often labelled as difficult or challenging, but that can also be seen in terms of attempts to exercise agency and control over one's environment or destiny.

8.3.7 Loss of Dignity

> *Regarded strictly as object, part of the material world of decay, the aging body can only destroy the dignity that consists in the self remaining at the center of its experience, freely determining the nature of its relation with the body. When experience is dominated by the body's dysfunction and disfigurement, dignity seems salvageable only through a sharp distinction between body and self to prevent the person's being defined in toto as disabled: the self repudiates the body to escape being contaminated by its deterioration. The body becomes a mere shell, a disguise. (Gadow 1983, p143)*

Suffering indignity was an important feature of Sheila's experience. When she realised, repeatedly, that she had removed her hospital gown and was lying in bed naked, the sheets bundled at the foot of the bed and the gown cast on to the floor, she was mortified. A sense of modesty was retained despite the fact that it was her that had removed the gown. Aligned (although not synonymous) with a loss of dignity was the experience of transgression of bodily boundaries as was observed when the surgeon attempted to examine Lilian's throat with an endoscope. She did not know who he was, and there were numerous other strangers clustered around the bedside. She was unable to articulate her distress but it was evident from her nonverbal body language that she felt something to be profoundly wrong with what was happening. Her distress conveyed a sense of outrage and fear at what might have been a sense of violation due to the intimacy of the procedure.

An important related concept to dignity is that of stigma. Stigma refers to something that is deeply discrediting (Goffman 1963) but something that should be considered in the language of relationship rather than attributes. It is not a thing in and of itself, but something that is manifest in the encounters the stigmatised individual has with others. Rita's rage at being classed as *"one of those"* (referring to people with dementia) not only illuminated her perception of wrongful treatment from staff, but also belied her own act of stigmatisation of those with dementia or confusion, as it contained an inherent judgment about the comparative extent to which a person's involvement in their care was worthwhile for those with and those without cognitive impairment. By not qualifying as a valid patient Alfie as stigmatised and his problems ere dismissively labelled as functional. Reactions of staff to Alfie's mysterious illness presentation alluded to this phenomenon. He did not fulfil the criteria for sickness as no definitive diagnosis is possible; yet he clearly did not belong in the *"kingdom of the well"* (Sontag 1978, p7). In Alfie's case, stigmatisation took place through the assignation of blame to his condition. Florence was stigmatised through being labelled as lazy, unwilling to help herself rehabilitate. A further criterion for being a proper patient is that of wishing to recover (as long as that is a realistic option), and staff were clear in their approval of this: *"she's really good, this lady, she just wants to get going".* Conversely intending to

recover when that is not an option is framed negatively and associated with being in denial. In essence then, most of the patients on the ward were subject to one form or another of stigma, and anyone subject to stigma was at risk of social exclusion as well as psychological problems such as anxiety, depression and self-esteem (Burgener *et al.* 2015). From a Bourdieusian position, stigma could serve the interests of the dominant group in the field by maintaining patients in their positions via the unspoken rules that align to ideas of how to be a proper patient (Link *et al.* 1999).

Closely aligned with loss of dignity is the notion of social death. Social death refers to how a person may cease to exist as a social being even before their physical body dies. A recent literature review (Králová 2015) proposes that the literature centres around three components to social death: loss of identity, loss of social connectedness and losses that accompany bodily disintegration. This is not a new notion; Sudnow's seminal work (1966) describing the end of life experiences of people in institutional settings identified various ways in which social death precedes biological death. Glaser and Strauss (1964, 1980) examined ways in which social and biological death were distinguished, with dying people losing aspects of their social worlds as they approach death, and point out how this process is enabled in ways in which they were viewed by others. Subsequently it has been proposed that social death is most likely for those with terminal illnesses, the very old, and people who have lost their essential 'personhood' (Sweeting and Gilhooley 1991). More recently, social death has been referred to as the loss of identity experienced by people as they enter the 'fourth age' (George 2010; Gilleard and Higgs 2015). As such it can occur long before biological death. A particularly strong example of social death witnessed during the fieldwork was the way in which Dot's family had gathered to say goodbye and surround her with cards, essentially awaiting her death while – surrounded by their grief - she continued to live.

A systematic review by Bridges *et al.* (2010) synthesised 43 qualitative studies relating to the experiences of older people in hospital. The three most prominent themes all alluded to different aspects of relational care: authentic connection, being seen as an individual, and being involved in decision-making. All three themes illustrate that the biomedical aspects of care are far from prominent in

the expressed concerns of older adults in hospital. The issues of importance to patients are social and psychological. The perspectives of participants in the majority of the studies in Bridges' review are reflected in the findings of the present study [32]

8.4 Conclusion

In this chapter I have drawn on selected aspects of suffering that emerged through the course of the fieldwork. I have attempted to deepen insight into each facet and its relationship with suffering. The resulting synthesis points to a concept of suffering that is broad-ranging and complex, and supports existing literature on the phenomenon of suffering. The first person narratives and second person observations of chapter 6 and 7 present complex and messy accounts of suffering through illness. The subsequent discussion in the present chapter has considered suffering from a more academic position, deliberating over concepts and contrasting philosophical perspectives. The former offers a way of conceptualising the themes of suffering experienced by the participants. The latter seeks to impose some kind of academic structure and rigour on these experiences. Neither endeavour stands alone; they rely on one another for a sense of wholeness. Each example from the fieldwork intersects with the literature in various ways and scholarship on suffering has been shown to extend across disciplines and to span epistemological traditions. The concept of suffering remains complex and expands with each new account of human experience. However, this chapter has examined some common threads to the concept and illustrated how identification with the literature can add richness to the narratives and *vice versa*.

Suffering is not a simple biomedical phenomenon. At a recent conference on the future of palliative care, Kellehear commented that palliative care is *"a social, psychological and spiritual concern with medical elements, not the other way around"* (Kellehear 2017). Despite this, hospitals, where much palliative

[32] However only four of the 43 studies adopted ethnographic methods and of these only one (Costello 2001) included those who were actively dying. The remainder utilised interview or survey-based studies and the participants had capacity and illnesses that were largely amenable to treatment

care takes place, are primarily designed around the biomedical model of illness. Suffering as it has been portrayed here did not readily offer itself up for therapeutic intervention within such a biomedical institution. Even though each of the healthcare professionals had differing and overlapping notions of what constitutes suffering, suffering and its alleviation did not fall within the remit of any particular profession.

In the next chapter I examine how the ideological positions considered in chapter 5 interfaced with the individual suffering experiences described in Chapters 6 and 7. I suggest that rather than biomedicine offering the cure to suffering, in many of these cases it was in fact the culprit, and much of the suffering that was observed was created or exacerbated by some aspect of the participant's hospitalisation. I draw on Illich's notion of iatrogenic harm to suggest that caring for people at the end of life within a biomedical paradigm was generative of suffering.

Chapter 9: Iatrogenic Suffering

> *"Suffering, healing, and dying, which are essentially intransitive activities that culture taught each man, are now claimed by technocracy as new areas of policy-making and are treated as malfunctions from which populations ought to be institutionally relieved"* (Illich 1975b, p210)

9.1 Introduction

In this chapter I consolidate the perspectives in the thesis up to this point. To summarise the relevant threads: the ideologies of care discussed in chapter 5 served to create particular cultures on the ward that were informed by different ideologies of care: rescue, rehabilitation and release. These ideologies at times clashed and this impacted on decisions and care. Further, the practices that characterised these ideological positions were largely taken-for-granted by staff. Patients admitted to the ward manifested a range of suffering experiences, which have been described in Chapters 6 and 7, and analysed in chapter 8. Suffering was frequently less to do with a patient's clinical conditions and more to do with the experience of hospitalisation and the social, psychological and spiritual consequences of illness, ageing and dying. This brings me to this present chapter, which addresses the question of why compassionate care was on the one hand such an obvious requirement for people in such vulnerable positions, yet appeared to be the exception rather than the rule. Geertz describes that one of the tasks of anthropology is to sort out the "*structures of signification… and [to] determine their social ground and import"* (Geertz 1973, p9) in a cultural group. To this end, I consider how the culture on Bluebell Ward contributed both directly and indirectly to certain forms of suffering. Finally, I suggest that this suffering remained largely invisible to the staff on the ward not because of a culture of cruelty or neglect but because the suffering originated from within the very culture that was expected to alleviate it in the name of compassionate care.

I argue that much of the suffering observed was either created or worsened by the experience of hospitalisation - either as a consequence of the environment of care, or through interactions with staff that were not compassionate, or

through having to undergo particular burdensome or distressing clinical interventions that were unnecessary or inappropriate. I develop this argument by exploring the concept of iatrogenesis, originally posited by Ivan Illich (1975a, 1975b). I provide a brief overview of Illich's work and suggest that many of his concerns have been actualised in contemporary healthcare, particularly as technological advancement has continued apace. Of particular relevance to the experiences of participants in my study were Illich's ideas about social and cultural iatrogenesis. Much of the suffering that I observed seemed to result not from participants' illnesses or symptoms, but from the lived experience of being a patient in hospital. This experience arose from the interventions and interactions that took place, and from the environment and culture of care. There were multiple ways in which the social, physical and psychological aspects of suffering appeared to be caused or exacerbated by aspects of being in hospital.

In order to explore this further, I propose that there were particular routes to iatrogenesis. I present examples in which ***interaction*** itself caused or provoked suffering. I explore the interpersonal context of care and demonstrates some facets of alienation and ambiguity that contributed to suffering. I then consider examples of where clinical ***interventions*** themselves caused suffering. Issues of futility and ethics are discussed. Finally, I examine how the ward ***environment*** contributed to iatrogenic suffering, including aspects such as social and physical isolation and fragmentation.

The chapter concludes with a reflection on why iatrogenic suffering persisted and moreover, how it appeared to go unheeded and unaddressed. Iatrogenic suffering appeared to be less readily recognised by staff than suffering that was more directly and explicitly related to the patients' clinical condition, such as that related to physical pain. I propose that the effect of clinical *habitus* was to render staff unaware of the environments of care that they co-created. They were like Bourdieu's 'fish' – unaware of the water in which they were swimming (Bourdieu and Wacquant 1992, p216). The healthcare environment had become so familiar to those working within it that it was possible to overlook the kinds of iatrogenic suffering described. Iatrogenic practices formed part of the taken-for-granted worlds of many of the staff; the connections between the two appeared not to be apparent to those habituated and socialised into the

environment of care.

9.2 Iatrogenesis

Illich proposed three types of iatrogenic harm. **Clinical iatrogenesis** referred to ineffective and unsafe practices, which in today's terms can be understood as clinical negligence, or malpractice. **Social iatrogenesis** referred to the impact of medicalisation on society more broadly, as manifested though the creation of dependence upon medicine for validation of a healthy status. Finally, **cultural iatrogenesis** resulted from the way in which medicine influences how a particular culture deals with illness, suffering and dying. Illich described medicine as a totalising system of knowledge that was productive of significant aspects of the social world.

9.2.1 Clinical iatrogenesis

Illich defined clinical iatrogenesis as the *"clinically verifiable, specific health-denying or disease-making effects of specific medical interventions"* (Illich 1975b, p79). This aspect of his work heralded what has become in today's healthcare climate a strong emphasis on patient safety (Sharpe and Faden 1998; Stollery 2007; Thornlow *at al.* 2009). Concerns about harm being inflicted as a direct consequence of medical practices have always formed part of the physician's mandate, since the time Hippocrates cautioned the physician to *"first do no harm"* (Hippocrates of Cos, transl.1923). In relation to the present study, clinical iatrogenesis included giving unnecessary, burdensome or harmful treatments or interventions. Paradoxically, attention to patient safety was sometimes interpreted as meaning a default to treatment over non-treatment, and intervention over non-intervention. The practice of medicine itself was not necessarily seen as productive of harm; it was the potential for neglect or oversight of some clinical diagnosis, fuelled by the ever-present threat of litigation. In this sense, even though patient safety was an explicit attempt to avoid clinical iatrogenesis, narrow interpretation of the meaning of safety was seen to be productive of patient suffering. Suffering was not, however, included in the list of recognised 'harms' within the organisation, and it was therefore possible for this effect to be reproduced.

9.2.2 Social iatrogenesis

Two aspects of iatrogenesis that were, for Illich, a much broader concern than clinical iatrogenesis, are the ideas of social and cultural iatrogenesis.

iatrogenesis referred to *"impairments to health that are due precisely to those socio-economic transformations which have been made attractive, possible, or necessary by the institutional shape health care has taken"* (p40). Illich argued that the practices of medicine, particularly in normal human experiences such as birth and death, had harmed society as a whole (1975). He was not the first to critique medicalisation in societal terms (see also the work of Parsons's work on 'the sick role' (1951), Zola's essay on medicine as an institute of social control (1972) and Foucault's description of the totalising impact of medicine (Foucault and Sheridan 1973)). But Illich's work heralded a turning point in recognising the responsibilities that medicine had taken on that were outside of its original boundaries, and – of particular relevance to the present thesis - he claimed that this had impacted adversely on society's innate resilience. He claimed that this process of 'medical colonisation' (p11) had eroded the internal supportive mechanisms of supportive societies, especially those around previously 'normal' activities such as ageing and dying, leading to a societal dependence on medicine. This in turn had given doctors power and control over what were once considered to be normal human events, such as birth, ageing and death.

Some thirty years after the establishment of the NHS, Illich observed that there was a flaw in the presumption that provision of free healthcare would lead to a healthier population and consequently a reduction in demand for its services. He claimed that the opposite had happened, a phenomenon he described as the 'Sisyphus Syndrome', wherein the more healthcare was provided to society, the more society came to depend upon it. Healthcare, he argued, in effect sponsors sickness by reinforcing a 'morbid society'. This concept has much in common with Kitwood's later description of the way that 'malignant social psychology' impacts on people with dementia (Kitwood 1997), depriving them of self-respect and diminishes their sense of personhood.

9.2.3 Cultural iatrogenesis

Closely associated with the idea of social iatrogenesis is Illich's notion of cultural iatrogenesis, whereby the medical enterprise *"saps the will of people to suffer their reality"* (p133). This was for Illich the most damaging form of iatrogenesis. He considered cultural iatrogenesis to be at work when health care is contextualised within medicine rather than being framed as societal wellbeing. When suffering is medicalised and illness is institutionalised, Illich suggested people lose their ability to experience their own bodies without the validation of the medical profession. This is in part what Foucault (1973) alluded to with his notion of the medical gaze. Illich argued that health professions have a culturally health-denying effect in that their practices damage individuals' abilities to manage the 'normal' events of human fragility, such as birth and death. He suggested that this had resulted from the progress of medical technology, and stemmed from a reluctance to accept suffering as a normal part of life, expressing concern over the *"effects of the social structure, social behaviour the social rituals built around the application of medical technology to people who are supposedly sick or who might become sick"* (1975, p80). Illich was influenced by Marxist perspectives on production, and considered that medicalisation was linked with over-industrialisation. He described a phenomenon whereby certain experiences that have cultural connotations – notably, birth and death - have become subsumed into medicine to the extent that the cultural aspects are diminished or lost. This has both an individual and a community aspect. Illich distinguished between pain and suffering in this regard, pointing out that pain has become just another biomedical phenomenon to be addressed with medication or other intervention. I suggest that suffering, with its broader social and cultural connotations has little or no place in the modern discourse of medicalised dying.

Kellehear (2009) notes that in general, patients seem to be suffering more despite medical advancement - *"not physically, perhaps, but emotionally. And his needs have not changed over the centuries, only our capacity to gratify them"* (p8). This perspective was echoed by Mercy, an agency nurse who worked several shifts across the hospital *"Medicine doesn't make you whole"*, she told me one evening. *"It doesn't heal."* She was a Christian, and explained to me that 'healing' meant two very different things in Christian and medical

terms:

> *"You can't be dying and healing at the same time. Why do people say things like - oh, she is 'fighting' an illness? It reflects their whole belief system, believing in aggression as the way we treat illness. I want light to shine here"*

9.2.4 Section Conclusion: Iatrogenic suffering

Although Illich's work remains popular among undergraduate and professional healthcare workers, the extent to which his ideas filter into contemporary healthcare discourse is debatable. Current understanding of iatrogenic harm tends to refer only to the first of his three 'harms' - that relating to the consequences of unsafe or ineffective practices, which I term clinical iatrogenesis. Patient safety has become a key driver in UK health policy (Department of Health 2000; Vincent, Burnett and Carthey 2014) as shown for example through the establishment of organisations like the Patient Safety Agency. Iatrogenic harm has been interpreted within contemporary medical literature as measurable actual or potential damage to a person's physical or mental health. Adverse events or harms are generally referred to as measurable negative consequences of clinical care, such as hospital-acquired infections or pressure sores, or mortality within 24 hours of surgery, and so on. The four significant 'harms' identified in policy at the time of this PhD study were pressure ulcers, falls, urinary tract infections and venous thromboembolisms (Madsen 2014). Suffering was not considered among these, despite earlier definitions of adverse events in the health services as being *"an event or omission arising during clinical care and causing physical or psychological injury to a patient"* (Department of Health 2000, pxii). One reason for this emphasis aside from impacting on patient wellbeing was the cost to the NHS of adverse events due to litigation - estimated at over £1 billion (Frontier Economics Ltd. 2014).

Contemporary definitions of harm do not include the concept of suffering. I therefore wish to draw attention to the overlap between iatrogenic *harm* and iatrogenic *suffering,* where the former refers to Illich's original thesis, but the latter extends to include broader ideas of wellbeing including ideas of health as being inherent 'aliveness' (Illich 1975b). Illich claimed that the purpose of

healthcare is to enhance the autonomy of a person to sustain or restore that aliveness or to adapt to changing environments. Suffering as a loss of aliveness transcends the narrow contemporary interpretations of iatrogenesis. Suffering is possible in the absence of disease, just as disease is not necessarily associated with suffering. Cassell (1999) cites numerous examples of people who appear to manifest severe suffering despite the relative absence of burdensome physical symptoms or disease, and vice versa - people who appear to have serious illnesses or distressing symptoms but nevertheless do not consider themselves to be 'suffering'. Most forms of suffering for the participants in this PhD study had little or nothing to do directly with clinical concerns.

This study was conducted in Northern Britain in 2015, under a relatively newly elected Conservative government and shortly after publication of the Francis Report, one of the most damning indictments of care in recent years. This was a very particular environment of care, from a political point of view, which meant that the priorities of care centred upon patient safety, efficiency and risk avoidance, rather than wellbeing and compassion. The term iatrogenesis is derived from *iatro* (physician) and *genic* (producing). It refers to harm caused by the action or inaction of the physician, although for the purposes of this thesis I frame *iatro* as referring to the healthcare system more broadly rather than just in the hands of individual physicians. I suggest that the political environment of care at the time of the study, with its focus on risk aversion, introduced (I suggest) additional aspects of iatrogenesis that were not explored in Illich's work because they were not at that time a prominent part of healthcare discourse.

9.3 Pathways to Suffering

In the next section of this chapter I argue that participants' suffering was caused by particular routes, or pathways, to iatrogenesis. I draw on examples from the fieldwork to illustrate these pathways, demonstrating the presence of clinical, social and cultural iatrogenesis in the practices on the ward.

9.3.1 Interventional Iatrogenesis

Interventional iatrogenesis refers to suffering that resulted from clinical

intervention in its broadest sense. This could be broadly linked with Illich's notion of clinical iatrogenesis and includes aspects arising from polypharmacy, adverse drug effects, hospital-acquired infections, and unnecessary or ineffectual surgery (Sharpe and Faden 1998; Mitty 2010). To this list I have added interventions in the context of end-of-life care. Therefore, this theme also includes tests which were considered invasive if associated with risk or discomfort, and particularly if their results were unlikely to lead to a change in treatment direction. The interventional route to iatrogenesis was perhaps the most obvious of the three routes, and the resultant suffering more tangible than those associated with interactions or the environment.

The examples I have selected demonstrate how interventions that were originally intended to have therapeutic effect, or to minimise risk, became associated with reduced wellbeing in the patients I observed.

Medicalising Intervention

The discussion with Ned's daughter (chapter 5) was an important example of this tension. Potential iatrogenic suffering - in the form of no longer being able to enjoy food - was narrowly avoided. If Ned's prognosis was thought to be good, then to withhold feeding through an enteral tube and risk aspiration through giving him oral food and fluids would have been tantamount to neglect. Yet if his prognosis were poor and quality of life had been the agreed priority, then forbidding him to eat the foods that he loved would have increased his suffering. Eating is a social and cultural act (Harris *et al.* 2002; Crogan *et al.* 2004), yet here it was framed as little more than a biological necessity.

Dr Basu framed the decision about Ned's feeding tube using the metaphor of a 'battlefield'. On the one hand, use of metaphor when explaining things to patients or relatives can avoid medical jargon by reduction of clinical interventions to easily comprehensible processes. Metaphors enable us to view one kind of a thing in terms of another (Lakoff and Johnson 1980). However, the use of this potential metaphor also has the ability to cause harm. A battlefield is not a pleasant image. Metaphors do not just describe similarities; they have a tendency to embed them. Suggesting that this clinical decision was akin to a battlefield was potent, conveying a sense of conflict and implying a clear sense of 'right' and 'wrong' as in a war between two sides. Using a conflict metaphor in

this context was unlikely to help collaborative decision-making.

Uncertainty about prognosis was associated with iatrogenic suffering. These concerns may have been worsened by aspects of the investigation into the misuse of the Liverpool Care Pathway (LCP) in which it appeared that patients had fluids withheld even when it was not clear that they were dying. Media reporting of this aspect described that death had been hastened intentionally through dehydration and malnutrition. However, at the end of life, artificial hydration through an intravenous drip can cause harm, for example by causing swelling or oedema of tissues around neoplastic tumours and hence increasing pain, or by placing pressure on kidneys that may be failing as a result of the dying process (General Medical Coucil (GMC) 2015). This was another example where a simple intervention could be seen as either necessary or inappropriate, depending on whether the team were in mutual agreement about the goals of care and the patients' prognosis. By focusing on the potential of the intervention to cause suffering, the appropriate way to act could become clearer. An important turning point for the conversation with Ned's daughter was the point at which she reflected on how much he loved shepherd's pie.

Ned's story can be viewed through each of the three ideological lenses discussed in chapter 5, and the 'right' decision would be different in each case. For example, if the goal was 'rescue' then the decision would be overwhelmingly in favour of enteral feeding to strengthen him, physically, and reduce his risk of aspiration. Any suffering associated with artificial feeding would have been acceptable because it would have been framed as a temporary measure, rather than a prohibition of eating ever again. If the goal was 'release' then quality of life would take precedence and his choice to eat shepherd's pie would be honoured. If 'rehabilitation' was the aim of care, then intensive input from speech and language therapists and dieticians might be indicated, perhaps involving testing out his swallow reflex with foods of different consistencies and amounts. Importantly, however, information about his own wishes and the perspective of his daughter had not been gathered prior to the clinical decision being essentially made in advance of the meeting described. It was through acquiring this additional information by 'accident' during this clinical encounter that Dr Basu shifted direction. It may have been that some distress could have been alleviated had a discussion about quality of life from Ned's

perspective taken place prior to the meeting. Importantly, Ned's own position was not considered as a part of the discussion, following his having been deemed to be without mental capacity. Yet even though he may not have had capacity to fully integrate the pros and cons of consenting or declining the feeding tube, meaningful involvement might still have been possible by – for example – finding out what his priorities more broadly were. What, for example, did he enjoy? And what gave his life meaning?

The literature illustrates that for people with dementia, clinical interventions such as enteral feeding and intravenous antibiotics are often carried out at the end of life without good evidence as to their effectiveness (Sampson 2010; Mahin-Babaei *et al.* 2016) and despite concerns about potential harms (Hughes *et al.* 2007). Eating and drinking were common causes for concern and presented challenging ethical dilemmas for the team and for patients' families. Conflicts often arose (as demonstrated through the discussions about Ned and Ellen).

For those approaching the end of life, iatrogenic suffering was a particularly important consideration. There came a point when the balance between risks and benefits of certain treatments shifted, and the risk of suffering through inappropriate or burdensome interventions became unacceptable. This difficulty is reflected in the literature. Concerns around dehydration, 'giving up' and 'losing the strength to fight' (Amella *et al.* 2005) are often cited reasons that families often insist on feeding beyond the point of utility and even to the extent that visible suffering ensues. This pressure from families could be informed by the impact of denial in the context of anticipatory grief, or it could indicate a lack of sufficient information regarding the perceived risks and benefits of the intervention.

Purposeless intervention

Michael's story was described in chapter 6. He had received two invasive surgical examinations for a suspected fistula[33] between his pressure ulcer and his rectum. Each examination was performed without anaesthetic. His ulcer was a Grade 4, which means it extended deep into the connective tissue around his

[33] *Abnormal connection between two hollow parts of the body; in this case, between a cavity pressure sore, and the rectum.*

sacrum. It was large enough to accommodate an apple. The skin around it was red and raw. When examined, he pushed his face into his pillow but I could still hear his scream. If there had indeed been a fistula between Michael's wound and his rectum, the continuous passage of faeces would have meant the wound would be unable to heal and would remain continuously infected. In such circumstances, the appropriate intervention would have been surgery. However, it was generally agreed that because of Michaels poor condition overall, surgery would be unlikely to be well tolerated and there was therefore a question over whether it would proceed even if a fistula were diagnosed. This begged the question as to why he had to endure not just one but two invasive examinations, and furthermore why these examinations were conducted without anaesthetic. The decision may have been informed by the fact that pressure sores were considered to be one of the primary 'harms' to be avoided, used as a quality measure in auditing patient safety across the hospital. Pressure ulcers were considered to be 'adverse events', and even though Michael was admitted with his ulcer already present, a worsening of the conditioning of the wound would render the staff vulnerable to investigation.

Interventions can cause suffering in the way that they often involve a transgression of bodily boundaries, as illustrated by Michaels' experiences and also by Lilian's, described in greater detail in chapter 7, when the surgeon attempted to examine her throat with an endoscope. She did not know who he was, and there were numerous other strangers clustered around the bedside. She was unable to articulate her distress but it was evident from her nonverbal body language that she felt something to be profoundly wrong with what was happening, some sense of violation. Suffering was caused when aspects of life that had previously been private were rendered public, and was associated with a loss of dignity and control.

Cascading Interventions

Ellen has already been discussed in detail in chapter 5. Her experiences exemplified the concept of iatrogenic suffering as a result of a cascade of clinical interventions.

> *On my way out of the ward I can hear the nurse and sister having a conversation about what time to restart Ellen's*

nasogastric feeding pump for her. 4 am is agreed. Each decision relates to quality of life but it is a fine balance - the family are undoubtedly also being treated by siting the NG tube, I find it really difficult to see her having this. She is oedematous, her legs are so swollen that they are shiny, they look as though they are made of plastic. They are cold to touch. Clear fluid seeps from an ulcer on her heel. As I leave the ward to go home, her family are milling around outside the entrance to the ward. "She vomited" they tell me, "so she's just being cleaned up".

Ellen experienced a cascade of iatrogenic interventions, beginning from her family's concerns about the lack of feeding and hydration she was receiving, and culminating in a nasogastric tube and intravenous infusion of fluids, and culminating with the establishment of a syringe driver with antiemetic and anxiolytic medication in the final hours of her life. Commencing a treatment was much less ethically challenging than withdrawing it, and furthermore no single clinician was in charge of her treatment plan from admission through to her death. Over the weekend, two different locum doctors reviewed her. This staffing structure meant that it was possible for her concerned family to continue to pursue the need for Ellen to be fed until a willing clinician was found. The dietician who eventually authorised the nasogastric tube had never met her before and responded to the demands of her distressed family, who were making it very clear that they considered that the hospital was starving their mother to death. This was the focus of much of the media's response to the misuse of the Liverpool Care Pathway and was therefore a particular Achilles heel for hospital staff in the political climate at that time.

Placing the feeding tube satisfied Ellen's family that the right thing had been done. Yet as the situation escalated, it transpired that this intervention led to far more suffering than she would have experienced had she been left to die naturally. Her family would not have been able to anticipate this. To do so would have demanded two things; firstly, that the clinicians spoke frankly and openly with her family about their uncertainty regarding Ellen's survival and the probability of her imminent death - undoubtedly an emotionally difficult and demanding conversation. Secondly, it demanded a confidence in the diagnosis and prognosis. Right until Ellen's last breath, clinicians remained uncertain as to

whether she had experienced a seizure or a stroke. This debate was something of a distraction from the real issues as she was dying in any case, as a result of the increasing burden of heart failure and renal failure. The focus on diagnosing stroke or seizure distracted the doctors from paying attention to what was apparent to many of the nurses, myself included, that she was dying from the day of her admission. Delaying open discussions about dying was associated with increased suffering for Ellen and for her family. Clinicians did not feel they were in a position of sufficient authority, or that they lacked some key clinical information to support their belief that she was dying. It was also perceived that her family were not ready to hear the news or that they were placing unreasonable demands, when in fact it is well established that normative responses to grief frequently entail a degree of denial and disbelief (Kübler-Ross 1973; Neimeyer *et al.* 2014).

Ellen was not alone in having experienced cascade iatrogenesis, and it was a story that many in palliative care will be familiar with. In an environment of uncertainty as to the potential success of a treatment, the default position is often to treat (Thornlow *et al.* 2009). I propose that Foucault's notion of biopower is useful in understanding the context of interventional iatrogenesis. He argues that there is an accepted characteristic of human beings and the degree of acceptability is defined and boundaried by certain authorities who are perceived to have the right type and depth of knowledge in relation to this truth. Furthermore, biopower dictates a particular relationship between 'letting die' and 'making live'. The examples used in this section have illustrated some tension between these two strategies which were both mechanisms of exerting control over human life. It was often considered safer in terms of doctors' duties to preserve life, as well as the pressures of potential litigation, to offer a treatment that doesn't work than it is to decide not to treat. However, knowing what is 'enough' in end of life care can have a huge impact on minimising iatrogenic suffering (Dunphy 2000).

9.3.2 Interactional Iatrogenesis

> *"We began before words, and we will end beyond them.*
> *It sometimes seems to me that our days are poisoned with too many words. Words said and not meant. Words said 'and'*

meant. Words divorced from feeling. Wounding words. Words that conceal. Words that reduce. Dead words" (Okri 1996)

I use interactional iatrogenesis to refer to iatrogenesis that arose or worsened in association with particular interpersonal interactions. It is well established that poor communication can increase suffering (Weiner and Roth 2006; Collier *et al.* 2016; McDonald 2016) and has the potential to reproduce situations of disempowerment and alienation. This can result from attending to difficult subjects in a way that causes distress, perhaps through a lack of sensitivity, or through omission or failure to talk about a subject that requires attention. In this section I explore examples where the consequences of interactions were not therapeutic, and where they arguably caused or worsened suffering.

Alienating Interaction

Rita (chapter 6) had end-stage heart failure, which caused severe breathlessness to the extent that she required continuous oxygen and could not complete a full sentence without pausing for breath. But her suffering was not to do with these aspects of her condition. The issue of greatest concern to her was the apparent invisibility she experienced as a result of her encounters with the doctors on their rounds. On the ward, it was common for patients to have some degree of cognitive impairment - whether a result of existing dementia or a consequence of delirium resulting from an acute condition - therefore the doctors were habituated to respond to acute problems without necessarily involving the patients about whom they were making plans and decisions. This was an example of the medical *habitus*; there were assumptions that a person with cognitive impairment would be unable to participate in discussions relating to their care, and that therefore it was unnecessary to try and involve them. Theoretically this kind of interactional iatrogenesis can be linked with Foucault's concept of the *'medical gaze'* (Foucault and Sheridan 1973). Essentially, this refers to the dehumanising effect for a person to be regarded by a physician with a view to diagnosing or evaluating the state of some disease or other, rather than being seen as a whole human being. This gaze for Foucault is uninterested in the person, specifically in their spiritual or emotional self, unless this relates in some direct way to the disease state of interest.

When Rita was first admitted staff considered that she was probably dying.

However, over a period of two weeks she had stabilised, and there was now talk of discharge. The fact that her mood had lifted somewhat after her clinical condition improved affirmed to staff that it had not been necessary to investigate this aspect of her condition. After her assessment by the mental health team, her mood was not mentioned again until the team began planning her discharge:

> *Doc: "She is medically fit for discharge and has capacity"y*
>
> *Nurse: "RAID saw her, recommended antidepressants but she declined, then she picked up"*
>
> *Physio: "When her physical condition is bad her mood is terrible, she has such breathlessness, but then when she is better she brightens up"*

Staff agreed that any low mood that might have been expressed while she was in hospital was related to her condition and to breathlessness rather than to anything else but, as explored in chapter 6, there were many complex and inter-related factors that impacted on Rita's suffering. Addressing her wellbeing only went as far as considering the interconnectedness with her apparent low mood with her physical ill health. It did not extend to consider the possibility for any other influencing factors. There were triggers to her mood that she herself was able to identify, such as the feeling that arose as a consequence of being treated as though she were invisible.

Apparently as a result of feeling ignored, Rita had withdrawn further and further from interactions with staff, particularly in relation to her mood. She conveyed the sense that there was not point as she considered that her concerns would be addressed in any case. This withdrawal in itself might have been viewed and framed as being related to low mood. Her answers to questions focused primarily on the clinical aspects of her condition such as her breathing, rather than the things that she had explained to me were really bothering her. This gave rise to a two reciprocal, mutually strengthening interactional process where Rita only gave staff information she thought they were looking for. Staff then became less aware that anything was wrong other than these physical concerns, and so their assessment narrowed further, exacerbating Rita's

original sense of being looked *at* without being engaged *with*.

Recent research observing older people's involvement in planning substantiates this further (Ekdahl *et al*. 2012) as staff were preoccupied with patient discharge, and perceptions were that patients were too tired, ill or cognitively impaired to involve in efficient and productive discussions. A patient survey (Maben 2008) conducted as part of a study on patient and staff experiences of care identified that around a third of patients in the sample considered that doctors and nurses mostly or always talked about them as though they were not there.

Meaningless Interaction

> *John, a physiotherapy assistant, comes into the room - glancing at me. "Hello, my name is John", he says to Vincent.*
>
> *"I know your bloody name is John", Vincent retorts, "You were only here this morning".*
>
> *"I know", John shrugs, "we have to say that. It's policy."*

The above excerpt was selected for inclusion here because it was emblematic of many other interactions that I observed. The key points that I intend to discuss here relate to how processes and policies aimed at enhancing and improving interpersonal skills actually had the opposite effect in some cases. This was further supported with examples from the fieldwork of other innovations and interventions on the ward which at face value appeared to contribute positively to the climate of care, but in practice were characterised by tokenism at best, or ineffective and wasteful interventions at worst.

John commented that policy required him to introduce himself by name, even though both he and Vincent shared a sense that this was somewhat ridiculous given that John had already been in once that day. The policy had arisen as a result of a recent national campaign in the UK. In 2015, a British doctor with terminal cancer spearheaded a campaign to encourage health professionals to introduce themselves by name (Granger 2015). Her campaign was far-reaching, with over a billion Twitter impressions for the #HelloMyNameIs tag. Many

healthcare embedded it in their person-centred policies, including distributing name badges with the #HelloMyNameIs prefix. The need to enhance communication skills in the hospital environment is broadly recognised, and the 'Hello My Name Is' campaign was just one example of many. John's statement that *"We have to say that, it's policy"* also suggests that he may have felt he had little agency in the judgement of whether or not it is appropriate to say something. Following policies and processes to the letter was one of the reasons suggested for the failure of the LCP (Neuberger *et al.* 2013).

Dr Kate Granger's original message was born out of a feeling that she was not being treated as a person, that she was confused by the array of professionals who were speaking to her, and that she required a level of connection with her healthcare team in order to feel safe. Yet subsequently her message was bureaucratised. Kate was talking about authentic connections, yet the above excerpt is an example of what Okri (1996) identifies as *"words just said"*, as opposed to *"words said and meant"*. This also resonates with Goffman's notion of scripted interaction (1971), in which the person uttering the words has a sense of 'line', or their performative strategy, as well as with the tokenistic use of innovations such as the Blue Butterfly scheme described in chapter 4.

Shaming Interaction

Sometimes, iatrogenesis could be caused through interactions, as in the following example. Florence (discussed in chapter 6) experienced alienation that was linked to staff reactions to her infections and odour. Increasingly, she withdrew from interacting with staff, culminating in a referral to the mental health team. In this section I focus specifically on those elements of her story in which the interaction might have exacerbated her feelings of shame and others' responses that conveyed disgust and caused stigmatisation.

The following excerpt from the field notes was taken from the day we first met:

> *[the room smells terrible. She has C Diff and is taking a strong antibiotic, vancomycin, for this. I am conscious of breathing very shallowly - it is a combination of the actual smell and the knowledge that it is highly infectious. She is in a side room, there is a warning notice on the door. We don plastic pinnies and gloves on even those who are not going to touch her. When we emerge, the locum doctor says "We can breathe again"]*

Almost all staff involved in Florence's care expressed aspects of disgust although most did so outside the room. For staff, there were numerous ways in which dealing with human waste was made tolerable. Most common seemed to be a process of desensitisation, which I address in chapter 4 through discussion of how the aversive smells of everyday clinical practice became something that staff just got used to over time. Although 'getting used to it' and 'tuning it out' were clearly effective methods of self-preservation for staff, they may have inadvertently caused suffering to patients who were unlikely to have been able to simply tune out these aspects of their bodies. One way in which this happened was that the bodily functions of eating and excreting ended up taking place in the same physical location.

Body work is recognised to be a core aspect of nursing practice. However, within nursing there are variations in status that are associated with differential levels of involvement with the body. Healthcare support workers have the most intimate contact with bodies and their effluents, whilst staff nurses have somewhat less. The charge nurse and sister have relatively little direct physical contact and the specialist nurses who visit the ward, such as the pain nurse or

the infection control nurse, have no physical contact at all. This is a subject that has been attended to in the literature, although perhaps more so in nursing than in medical scholarship (Holmes *et al.* 2006; Schnall *et al.* 2008; Simpson 2012). Doctors have less direct contact with the body; pathology results can be derived by looking at the online patient record, and nurses provide sufficient history regarding frequency of vomits and other embodied aspects of illness. Lawler suggests that this distancing is associated with the status of the medical profession as compared to nursing (Lawler 2006).

Douglas notes that dirt is only dirt when it is perceived to be out of place (1966, 1970), and that in the ordered and sterile environment of the hospital such signs of bodily effluent are particularly offensive. The doctor seemed indignant about having to use her own 'personal' stethoscope. Even though wiping it with chlorhexidine would have killed any bacteria or other pathogens she appeared to remain aggrieved that she had had to use her own equipment to examine Florence. She seemed to view its contact with Florence as somehow polluting her clean equipment. Lawler's study of somology identifies that body work is frequently hidden on the ward, and suggests that this serves to purposes. Firstly, it preserves the dignity of the patient. Secondly, it also protects staff from damaged esteem arising from association with messy bodily functions. The doctor in this case was accompanied by a junior colleague, and also was witnessed by myself. As such the encounter transgressed the usual unspoken rules of privacy about this kind of work. Further, the doctor had already alluded to the fact that she disapproved of Florence's apparent reluctance to engage in rehabilitative activities: *"She reminds me of my grandmother; bone idle."* It has been suggested (Twigg and Martin 2015) that liking a patient makes being involved with their bodily functions less aversive (Twigg *et al.* 2011). This may have exacerbated the doctor's perspectives.

Although Florence did not attest to it explicitly, it appeared that the cumulative effect of being isolated in a side room, witnessing directly a range of responses of health and social care professionals to the odours in the room, and the diagnosis of two pervasive infections would have had a profoundly isolating impact that was additional to the suffering inherent in her illness itself. Breaking this down, there may have been ways in which this could have been mitigated; some intentional human contact that wasn't focused on a clinical intervention,

an offer to wash her hair, or some interaction that did not convey how stigmatised she had become.

9.3.3 Environmental Iatrogenesis

In this section I examine how the ward environment represented a third iatrogenic route to suffering. Even though the environment of care was a strong focus in acute care policy in relation to older people in hospital, numerous studies (Moyle *et al.* 2008; Porock *et al.* 2015) identify that there are aspects of the hospital environment that are unsuitable for older people - particularly those with dementia and cognitive impairment.

Healthcare environments within the NHS are largely designed based on the principles of being able to deliver safe and effective clinical care (Devlin and Arneill 2003). Less prominent is the argument that the environment of care can be an end in itself, and can aid health, healing and wellbeing through well-considered design. Evidence to date has demonstrated connections between the physical environment of the hospital setting, and its impact on wellbeing in older people (Firth-Cozens and Cornwall 2009) particularly people with cognitive impairment (Brereton *et al.* 2012) and those who are near the end of life (Waller *et al.* 2008; Reyniers *et al.* 2014). In an environment such as Bluebell ward that was characterised predominantly by brief admissions of acutely ill patients, it was less of a priority when compared to the safety and efficiency aspects of design.

Isolating Environment

The environment was not just physical. In considering how the environment impacted on wellbeing one must also think about the extent to which it permitted or inhibited opportunities for interaction. Perhaps the most obvious way in which opportunities for interaction were inhibited was through the use of side rooms on the ward. Side rooms on the ward were used for several purposes. Primarily they were for patients who could not be in a shared bay for reasons of safety. This might be because of cognitive impairment that meant they did not remain in their own allocated space, or it might have been because they had an infection. Both of these states were considered to pose a risk to other patients. A third reason for being given a side room related to their clinical condition. A

newly admitted patient who was unstable might be moved into a side room until their condition had stabilised. Finally, side rooms were often used when a person was thought to be dying - partly as a means of providing privacy and dignity and enabling their families and loved ones to visit freely outside the usual visiting times, but also partly to protect patients on the shared bays from witnessing dying that may cause distress (Kaufman 2005).

Sheila was put in a side room to minimise disruption to other patients, and then when she developed MRSA she was kept there. Days turned to weeks, and her mood and level of disturbed and distressed behaviour worsened. Some studies suggest that the visible presence of staff can be reassuring for people with dementia (Edvardsson, Sandman and Rasmussen 2012). Kitwood (1997) and Brooker (2007) suggest that taking the perspective of the person with dementia can help to make sense out of certain kinds of behaviours, and that rather than view a behaviour as disruptive or difficult it is best seen as a means of coping with a particularly adverse situation. From this perspective, Sheila's behaviour could be seen as a means of coping with the disruption of having been isolated from others.

For people at the end of life there can be fear around being alone or being abandoned. This can be experienced directly or at times – as in the following example – experienced by a family member. Arthur had dementia, and came to hospital with a severe chest infection. He was given intravenous antibiotics but his vital signs remained unchanged, and it was decided after 48 hours to put him on the Integrated Care of the Dying Pathway. Antibiotics were stopped and he was given midazolam (an anxiolytic medication) to try and calm his agitation. He was placed in a side room 'for privacy'. His daughter Ruth remained with him continuously, the door closed and the curtain pulled around. Over the following day he spent more and more time asleep. In the following extract, two sides of the same apparently objective situation were demonstrated:

> *Nurse to me (in corridor, around an hour after giving midazolam):*
> *"He is settled now. That daughter is wonderful, hasn't left his side"*

I spoke to his daughter by his bedside later that day. Ruth told me that she was worried he had been needlessly sedated quite soon after admission without

giving him a chance to recover. She added that the agitated behaviour the nurses had identified was “normal for him” and was part of his dementia.

Ruth to me: “It’s his dementia. They've written him off”.

Once it was decided that Arthur was dying he and Ruth were essentially left to their own devices. Staff perceived that she was doing a good job of caring for him and mostly left them alone until he died the following day. They did not identify Ruth’s anger and concern about the possibility that his agitation had been misinterpreted by staff who did not know what was normal for him. Staff perceived that they were giving Ruth and Arthur privacy; Ruth perceived that they had been abandoned. The suffering created by this isolating environment could be seen as a manifestation of cultural iatrogenesis. Arthur’s dying had to be sanctioned by the doctors, and this dictated all of his subsequent interactions with the clinical team. However, Ruth’s reaction conveyed a sense in which his dying was potentially misdiagnosed, but she was powerless to influence the direction of care that had been decided upon and mandated by the implementation of the care of the dying pathway.

Disruptive Environment

The ward routine described in chapter 4 served the purpose of rationalising and coordinating care, but this routine was probably very different to what was usual for patients, even those who had been admitted from other institutions such as care homes. Institutional environments are known to increase physical and psychological dependency. Goffman’s notion of a ‘total institution’ described how the domains of everyday life (sleep, work and play) that are normally segregated, take place in the same location in a way that is organised by others (1968). Taking on the identity of a patient involved surrendering aspects of one’s former self, as symbolised by clothing, personal possessions, and routines. This was accompanied by a loss of power, or to use Bourdieusian terms, a reduction in social capital.

In chapter 4 I described the sounds and noises that took place on Bluebell Ward. Sound becomes noise once it is perceived to be unwelcome (Devlin and Arneill 2003). The healthcare literature suggests that noise levels on wards are associated with perceptions of invaded privacy (Baillie 2009) impact on patients’ sleep (Xie *et al. 2009),* wellbeing (Cunha and Silva 2015)and impaired

communication. Florence Nightingale, writing more than 150 years ago, observed that *“unnecessary noise…is the most cruel absence of care which can be inflicted either on sick or well”* also pointing out that it is the sudden, sharp sounds that are more likely to disturb than the low, background level of noise. She added that *“a nurse who rustles is the horror of a patient, though perhaps he does not know why”.* Finally, she considered that *“all hurry and bustle is peculiarly painful to the sick”* (Nightingale 1959, p44).

Sometimes sounds were neutral in terms of their impact on distress and suffering. But at other times they could be associated with suffering, either because of the confusion and intensity - as was the case for Lilian in her sensitivity to the adverse effects of overstimulation. Alternatively, the *meaning* of the sound could cause suffering as for example when patients heard other patients crying out, or - more obtusely - where the sound may have evoked a particular emotional response, as in the following example:

> *Vincent is waiting for medical investigations of his anaemia. The doctors are concerned he may have myelodysplasia, a precursor of myeloma. The test for this is a bone marrow biopsy, which involves drilling into his pelvis to extract a small tissue sample which is examined under a microscope for abnormal cells. His room is positioned midway down the corridor, opposite a utilities cupboard where maintenance workers are rerouting some wiring. This involves a certain amount of hammering, and drilling. Also heard is the continuous sound of Sheila from the room next door "No! No!!" and Lilian, a little further down, screaming "They've taken my eyes". The drilling continues today. Hannah tells me it is driving her mad. She is the third person to tell me that today. “It’s been going on for months”*
>
> *I only notice this when I sit beside him; the sound enters my field of awareness and I realise I have just been thinking about his biopsy. I cannot separate the two – the thought of the procedure as his bone is drilled, and the sounds of the engineers at work. I recall how just the sound of the dentists’ drill used to make my teeth ache.*

When the procedure is explained to Vincent the doctor raises his voice over the sound of the drilling. "No, thank you very much", Vincent says, glancing at me and looking fearful. Small wonder, I reflect

Merleau Ponty's phenomenological account of perception identified the embodied nature of perceptual stimuli and the association of such stimuli with meaning for the perceiver (Merleau-Ponty 1962; Marcoulatos 2001). The stimulus of the drilling noise arrived already associated with a particular meaning, judged in a particular way. My interpretation was that it was an unwelcome reminder of the invasiveness of a bone marrow biopsy. The drilling sound, the imagined procedure, and the mingling of the inner and outer worlds, aligned with Merleau Ponty's notion of 'creative receptivity', in which active perception created the meaning of the sensory stimulus.

When patients were dying, there were attempts to create some protective wall of silence around them; for example, they might be moved to a side room, or if in a bay, have the curtains drawn around their beds. This illusion was visual rather than auditory, it offered a demarcation and separation from the hubbub of the rest of the ward, but even with the boundaries offered by curtains and doors, sound travelled easily on the ward. There was nowhere that was silent. The closest thing to a quiet space was the tiny doctors' office tucked at the back of the ward, to which refuge junior doctors frequently escaped when they needed to make a decision or read through a set of medical notes.

Little has been written about noise and sound in the context of dying on the ward. Sound is often associated with activity, and silence with stillness (Atkinson et al. 2008). The use of silence in caring for the dying person is generally considered to be an important means of creating a compassionate space (Back *et al.* 2009) yet much has been written regarding the noisy environment of care in hospital (see for example (Busch-Vishniac *et al.* 2005; MacKenzie and Galbrun 2007; Khademi and Imani 2015). Studies that do address perceptions of noise from the perspective of patients and staff do so through the use of interviews and questionnaires (Shiers *et al.* 2012). The impact of noise on patients who are seriously ill or dying, or who do not have capacity to complete a questionnaire, is not known although it might be reasonably presumed that noise would impact in profound ways upon wellbeing.

The fieldwork illustrates the impact of noise on patient participants, supplementing that which is already known from the literature. However, to the existing knowledge I suggest that the perceived origin and meaning of the noise or sound may have been as important as its level or intensity.

9.4 Discussion

A memoir of the work of Ivan Illich is subtitled *"Less medicine, More health"* (Scott-Samuel 2003). Perhaps this was the inspiration behind the title of the recent investigation into the Liverpool Care Pathway: *"More Care, Less Pathway"* (Neuberger *et al.* 2013). Illich was one of the first to challenge medicine's dominance but at the time of publication his thesis was unwelcome, and criticised as being unempirical, idealistic and vulgar. During subsequent years, however, Illich's thesis has been recognised as holding significant social import, and the development of palliative care has taken place alongside a growing critique of medicalisation that arose from the discussions catalysed by his work. His work offers important insights into the suffering experiences of people dying in acute hospital settings. Healthcare environments, and a range of processes intended to guide professionals in their care of the dying, have contributed to aspects of care that are less than ideal. This includes over-zealous prescribing of investigations and treatments that have little chance of success, sedation, seclusion and ambivalence in discussing death and dying leading to last-minute discussions with families. This thesis has demonstrated that suffering does not relate solely to people's illness experience but to their broader experience of the hospital, and the environment, interactions and interventions that they encounter.

Suffering in Peripheral Vision

This chapter has drawn upon Illich's work to examine iatrogenesis and has extended this idea to propose the existence of iatrogenic suffering. The most enduring of his propositions is clinical iatrogenesis, but I have suggested that of the three types of iatrogenesis that he discussed, it was the social and cultural elements that were perhaps the most intimately linked with ideas of suffering as a holistic experience. Simple avoiding unintended clinical harm did not address the wider goal of alleviating suffering but often caused unintended suffering.

During the study, iatrogenesis appeared to be recognised most readily where there was conflict between the ideological approaches underlying care decisions. Health professionals seeking to identify suffering related to illness, who were themselves enculturated within the hospital and its routines, may have been oblivious to the harm that was caused by this experience and to which they may have contributed through actions or inaction. The iatrogenic suffering observed was either not tackled by staff, or else it passed without comment among them. There was a paradox. All the staff I spoke to expressed a deep wish to care for patients properly, to spend time with them and to do the right thing. All expressed ambivalence about the increasing requirement for data collection about ward activity for regulatory purposes, and other activities that they considered detrimental to patient care such as moving nurses between wards to manage staffing levels. Yet in my observations there were many times that patients who appeared to me to be suffering were ignored by staff, who - whilst often busy - were just as frequently to be found talking in the nursing pods or chatting with patients who were cognizant and able to engage in conversation.

Bourdieu's concept of habitus can explain both the continued causation of iatrogenic suffering, and the apparent obliviousness of some staff to iatrogenesis. The examples indicate that even where certain members of staff were able to recognise iatrogenesis, they were unable to act to alleviate it because of their comparatively poor stocks of social and cultural capital. Staff were *aware* of suffering, and could explain it with reference to particular patients, but they could not describe or define it. Moreover, much of the suffering I observed was peripheral; it was easy for it to go unnoticed. Morse's work on conceptualising suffering (Morse and Carter 1996; Morse and Penrod 1999; Morse *et al.* 2003) proposes that suffering expressed emotionally (for example, through crying, or through words) is only one form of suffering. She proposes that 'enduring suffering' is a significant phenomenon that is easy to ignore, takes place where a person does not feel sufficiently safe to express themselves and is intimately associated with ideas about the future, and hope. Vincent's flat, emotionless responses to John belied much more than his words conveyed. Taken at face value, he was labelled as non-compliant with

treatment, belligerent, even disruptive but his stories demonstrated deep suffering. They included his ongoing grief for his wife, his reluctance to prolong his own life which he was now bored of living, withdrawal from nicotine as he was forbidden to smoke his cigars, his wish to go home and live freely against an increasing sense of fear that he would be unable to do so safely or affordably. All of these issues aggregated to suggest deep suffering, much of which was iatrogenic, yet to many of the staff, suffering was framed in terms of his breathlessness or his social care needs.

Most nurses in the UK will have encountered Maslow's 'hierarchy of needs' as part of their training or professionalisation (Maslow 1943) This needs-based model of nursing has shaped many shared practices across a variety of settings. Certainly, as nursing is increasingly influenced by medical and technological systems of care, hierarchical systems such as Maslow's have become interpreted as meaning the meeting of physical needs should take precedence over the meeting of any higher-order needs. Some critics suggest this has led to neglect of the spiritual and social aspects of existence. Social suffering such as Sheila's isolation, or Florence's sense of alienation, may have been less easy to identify than physical needs such as an imbalance of electrolytes, a symptom requiring a medication, or a wound needing dressing, but they had a significant impact upon quality of life.

In "Rhetoric", Aristotle suggested that a prerequisite for pity is for suffering to be perceived as being sufficiently serious to warrant pity (Barnes 1982). So, the observer will make a judgement that relates to seriousness, and the response to suffering will be proportional to this. Every patient on the ward was there because of some decrepitude or disease relating to old age. It could be argued that they were all suffering, to differing degrees. It was necessary for staff to draw some kind of line between what was considered serious and non-serious suffering, in order that they could appropriately direct their finite resources and care for those most in need. On one level this may have been related to self-preservation. On another level, however, staff might have responded to suffering only insofar as they felt able to do something about it. Suffering might have been recognised but not responded to, or it might not have been recognised in the first instance.

9.5 Conclusion

This chapter consolidates the findings of this thesis to present a theoretical perspective about the nature of participants' suffering. I suggest that iatrogenic suffering not only involved biomedically-focused notions of harm but also incorporated social and cultural components. Focusing primarily on enhancing compassionate care did not address the core issue which was that there were forms of suffering that had just as negative an impact on patients as symptoms such as pain, but these tended to go unrecognised.

I have opened up a debate as to why it was that these less tangible manifestations of suffering seemed less visible in the overall care of patients. This was explored by utilising Bourdieu's theory of habitus in conjunction with Illich's position to analyse the structures that enabled causation and reproduction of iatrogenic suffering. Those forms of suffering which arose as a consequence of hospitalisation often went unrecognised. I suggest that this was to do with the fact that the practices were deeply embedded in the social structures of the ward were the very ones that created or exacerbated suffering, and therefore those agents who played a part in their enactment were simply reproducing practices within their habitus.

Broadly, suffering caused by aspects of the clinical environment of care had become so embodied as habitus that they were taken-for-granted, matters removed from consciousness. This habitus was formed of those aspects of professional life that staff have been socialised into – to greater or lesser degrees. The focus on risk aversion, for example, had become so embedded in clinical discourse that the practice of defensive medicine may not always have been have been something that clinicians were aware of doing. This argument leads to my final chapter in which I begin to explore what implications my findings might have for clinical practice and for education of healthcare professionals. If (as Bourdieu suggests) habitus was not fixed, then attending to internalised structures through providing ways of experiencing the clinical environment may enable future shaping of professional habitus in a way that enables recognition of iatrogenic suffering.

Chapter 10: Engaging with Suffering

"For seven days and seven nights [Job's friends] sat beside him on the ground, and none of them spoke a word to him, for they saw his suffering was very great" [Job 2:13]

"If there is a meaning in life at all, then there must be a meaning in suffering. Suffering is an ineradicable part of life, even as fate and death. Without suffering and death, human life cannot be complete" (Frankl 1964, p88)

"Constant exposure to suffering, coupled occasionally with a feeling of being taken for granted, can induce feelings of helplessness and even despair. Or it can happen that individuals may find themselves performing outwardly generous actions, merely for the sake of it – simply going through the motions [….] when left unchecked, this can lead to insensitivity towards others' suffering" (Dalai Lama, cited in Scheler 1970) p.129)

"So much suffering is unnecessary, invented, no good purpose.
Good news: Because this type of suffering is made up,
we can change it.
We need to make the distinction between necessary and unnece ssary suffering.
Our role is to relieve suffering, not add to the pile" (Miller, 2016)

"If I recall now that the possibility of stopping this infernal machine in its tracks lies with all those who, having some power over cultural, artistic, and literary matters, can, each in their own place and their own fashion, and to however small an extent, throw their grain of sand into the well-oiled machinery of resigned complicities" (Bourdieu 1972, p65)

10.1 Overview

The NHS Constitution states that its members *"ensure that compassion is central to the care we provide and respond with humanity and kindness to each person's pain, distress, anxiety or need"* (Department of Health 2013, 05). At the

start of this thesis I set out to explore in greater detail the nature of compassion, suffering, and the experiences of older people in hospitals. I challenged several assumptions in contemporary healthcare policy and explored how factors outside individual volition contribute to the overall experience of compassionate care. In this chapter I examine to what extent I have successfully challenged this assumption. I propose that the thesis has demonstrated some of the complexities inherent in providing compassionate care and discuss some potential applications of the findings in education and clinical practice. Firstly, a model for guiding multidisciplinary team decision-making in older person's care is considered, based upon the premise that suffering results from misalignment of goals of care within the dominant three ideologies. Secondly, I reflect on my experiences of observing care as a researcher, rather than as a nurse who might otherwise have become identified with the business of the tasks that required completion.

10.2 Introduction

The thesis has considered several less visible aspects of patient experience and clinical practice that impact on compassionate care – including presentation of suffering, conflicting ideologies of care, and iatrogenic practices.

The aim of this concluding section is to suggest how this thesis might help make suffering, and its antecedents and consequences, more visible to stakeholders. This includes health and social care professionals and students who are involved daily in the planning and delivery of care, and managers who may be unaware of the unintended negative consequences of the kinds of monitoring and regulatory processes that they are beholden to. It may also speak to prospective and ex-patients and their families who may need to carefully consider the relative benefits of hospital admission near the end of life. I consider how these insights might lead into changes or improvements in practice for individuals and organisations. I consider the implications of my findings for healthcare educators, and critically examine the limitations of the study, making suggestions for policy makers, future research studies and innovations.

The launching point for this thesis was the Francis Report's damning accounts of patient experience and subsequent recommendations regarding training and monitoring of compassionate care. I challenged the premise of a compassion deficit, suggesting that this is based on assumptions regarding the nature of compassion which are contested. The report categorised kinds of harms into a typology that included over-treatment, delayed or wrong diagnosis, failure to treat, and psychological harm (conceptualised as 'feeling unsafe') (Vincent, Burnett and Carthey 2014). In this, it adhered to a narrow view of iatrogenic harm and did not address the broader issue of suffering. The report recommended attention to developing a compassionate culture, in which members hold shared basic assumptions, learn as a group how to adapt, and teach new members of the group the 'correct' way to think. Proposing that culture can be changed by increased monitoring and regulation revealed an unquestioned premise that the potentially obstructive or immovable aspects of healthcare systems themselves were blameless in creating the kinds of conditions that were described in the report.

My investigation took me on a journey which initially deconstructed the concept of compassion, identifying crucial elements within compassionate care such as the recognition of suffering, and the motivation and resources to take action to respond to that suffering. This in turn led to a detailed exploration into those people who were most vulnerable to the kinds of poor care detailed in the report; older people in acute hospital care. I was concerned with studying the nature of such suffering and finding out more about what gets in the way of compassionate care. This led me to present a series of narratives, each of whom manifested a particular complex picture of suffering.

I found that such issues could not be meaningfully explored without examining the nature of suffering experienced by patients in this setting, the relationship between the goals of clinical care and the phenomenon of iatrogenic suffering, and the interactional processes taking place between professionals involved in delivering care to older people. The cultural context of task-orientated care and risk-aversion, within a bureaucratic organisational structure, appeared to have

created a system in which the provision of compassionate care was difficult, although not impossible.

In my thesis, I have reflected upon moments of tension between my newly found practice as a novice ethnographer, and my prior (and more embedded and habituated) roles as a nurse and latterly an educator. Adopting the former role, I was an observer of the field, and even though at various times I became a participant (at times unwillingly), my role was primarily observational. Therefore, this concluding chapter is to some degree an expression of the tensions between these positionalities. I was able to sit and observe practices, write representative accounts of my participants, and consider theoretical perspectives that can offer insight into these stories. I was an observer in the field. As a nurse, however, I am a player in the field. I am a part of the system that I describe. I educate students to become players in that field.

Prior to the thesis I considered that the needs of older, vulnerable people at the end of life were not being met. Having completed this investigation, I am more convinced of this than ever. A further aim of the thesis was therefore to make tentative suggestions about clinical practice and education. These suggestions are ideas. They have not been tested (although this might be a possibility for future work); they are born of my own reflections as to what I have learned on this journey.

10.2.1 Summary of key findings

In chapter 5 I proposed that the focus of care was often dictated by practices that were ideologically informed and often associated with particular professional roles. Further, I illustrated some ways in which problems could arise when care was transitioning from one ideologically-informed approach to another. I suggested that the ideology of rescue remained the dominant influence on decisions relating to care – particularly in this clinical environment where prognosis was plagued by uncertainty - and this was itself informed by wider societal and institutional priorities. Chapter 6 and 7 described different

ways in which suffering was manifested, alluding to the complexity and subtlety of many of the experiences of patient participants.

This was placed in a theoretical context in chapter 8. I argued that comparatively little suffering resulted from the patients' clinical disease; the vast majority of suffering experiences observed appeared to be derived from the experience of hospitalisation itself. chapter 9 proposed that the phenomenon of iatrogenesis can influence suffering in a range of ways. Iatrogenic interactions caused patients to feel disempowered, angry and anxious. Interventional interactions could provoke distressing physical symptoms or a sense of loss of control. Finally, environmental iatrogenesis could lead to isolation, disconnection or fear.

10.3 Implications

Bourdieu resisted the idea that his sociology was just to be used for explanatory purposes, instead arguing for the utilisation of theory as a form of social action. For Bourdieu, social change becomes possible through the awakening of consciousness that can take place when there is successful identification of the dissonance between a particular field and a particular habitus. Habitus is not static, but is constantly reproduced through the interaction of agency and structure. He believed that habitus can be challenged and changed, through a process of reflexivity. This is fundamentally a pedagogic argument; through reflexive sociology, one can be made aware of these forces, and once in the conscious domain they are amenable to change and challenge. For Bourdieu, habitus enables one to transcend traditional dichotomies between the individual and the social or environmental and to demonstrate how these are mutually interdependent, and that agents are both formed by, and formative of, their environments. Habitus cannot be abstracted from field, and vice versa.

This has important implications for thinking about compassion; arguments in the literature relating to the 'compassion deficit' focus primarily upon either individual attributes (including moral distress, burnout, desensitisation and so on), or institutional responsibilities (such as neoliberalism, autonomy and bureaucratisation). Yet few analyses recognise the interplay between these. Bourdieu offers a means of bridging this gap. The examples in this thesis have enabled an examination of how field, habitus and doxa work in different ways to create certain kinds of practices, and this permits the existence of some types of suffering over others. We need to understand the inhibitory forces that act on compassionate care rather that focus on regulatory interventions.

The relevance of Bourdieu's work to this thesis rests upon the fact that it attends to those aspects of culture that were not explicitly rational or meaningful; it offers explanation as to why habitual modes of action were perpetuated among rational actors, and this includes clinical practices that may seem counterintuitive, or inappropriate, or at times even potentially harmful. This is where the potential for iatrogenesis lies, it is invisible to those who are

causing it not only because they are habituated to ways of doing things but because it entails the reproduction of ways of knowing that are not known to the actors themselves. The actors are themselves blind.

There are several areas where practice change might be indicated. For example, if we were able to identify the most appropriate approach to care based on patient preference, and equitable contributions from the full range of experienced and knowledgeable staff – rather than default to rescue - it might be possible to avoid iatrogenic suffering. Another example where care could improve is through enhancing understanding of sufferings' complex manifestations. The two broad suggestions I make here pertain to how this new knowledge might inform practice. The first relates to the potential use of observational methods in health professional education to challenge habitus. The second refers to hospital practices in which decisions pertaining to older patients are made, and suggests approaches to multidisciplinary team discussions that can draw out a patient-centred approach by refocusing on goals rather than defaulting to traditional professional alignments with particular approaches to care.

10.3.1 Observational Methods in Health Professional Education

A key finding of this study has been the extent to which many clinical practices were taken for granted. As such, many such conflicts were played out multiple times along familiar themes.

One way of conceptualising this is to argue that individuals were blindly directed by habitus. Habitus dictates action and determines the type of agent an individual will be in the field. This means that individuals were largely unaware of the influence of habitus on their actions. Yet Bourdieu argues that doxa and its resultant habitus strongly directs actions in the field, and at times these actions were not in patients' interests. Accordingly, any effort to render taken-for-granted aspects of habitus more visible to the agent can contribute to changes in professional practice.

Bourdieu suggests that habitus - because it is formed of inherited ways of doing things - can develop its own momentum which can mean that these patterns can persist even after the original impetus for doing them has vanished. Thus, the investigation into the alleged misuse of the Liverpool Care Pathway led to the withdrawal of the pathway and instructions to create 'care plans' rather than 'care pathways'. Practice has been notoriously slow to change in the aftermath of this, even though the pathway was ostensibly withdrawn from use immediately. The habitus of capturing the pathway of dying in an evidence-based algorithm had become embedded in the shared practices of the clinical team. As Bourdieu argues, *"if agents are possessed by their habitus more than they possess it, this is because it acts within them as the organising principle of their action and because this modus operandi*[34] *informing all thought and action (including thought of action) reveals itself only in the opus operandi"*[35] (1972, p18).

Reflexivity: research experience and clinical implications

Bourdieu did not consider it necessary to take a single perspective on sociological phenomena, and indeed within his broader framework of habitus this would not be considered possible (Bourdieu 1999; Kenway and McLeod 2004). Reflexivity does not allow the observer to converge on a single truth; rather, it allows an individual to engage with their own habitus, in a *"systematic exploration of the unthought categories of thought which delimit the thinkable and predetermine the thought"* (Bourdieu and Wacquant 1992, p40). Reflexivity forms an important part of Bourdieu's sociology and is also increasingly recognised as a powerful method for changing professional practices within nursing (Nairn *et al.* 2012), medicine (Neighbour 2005) and in research of health and social systems (Mason 2002; Rae and Green 2016). Reflexivity in this case involves intentionally place oneself in discomfort and to permit this to lead to insight into one's habitus. This was certainly my experience during this study; my comfort zone was in my nursing experience, establishing myself in an

[34] Habits of working

[35] Need to work

accepted position within a professional group, and a range of other practise aimed at securing my position in the social field of the clinical ward. As a researcher I was repeatedly uncomfortable, moving between groups of professionals, resisting contributing to discussions about care that were taking place in my familiar language. But it was this intentional separation from the field that I felt enabled me to challenge so many of the things I had previously taken for granted. This led me to postulate about whether this process itself might be beneficial to other clinicians who have become accustomed to particular ways of being, and whose practices were deeply embedded in taken-for-granted habitus.

Habitus: inertia and growth

My first suggestion pertains to the use of observational methods derived from anthropology in clinical education. As a nurse, I was new to ethnography. I learnt some skills by reading books and speaking to anthropologists and trying it out on buses, in libraries and shopping centres. I developed my own style of observation. It was a paradigm shift; suddenly I was observing a familiar world through eyes that were learning to unpick aspects of practice that I had hitherto taken for granted, and to see things from multiple perspectives. Most notably, time spent with patients illustrated to me how things I had previously presumed to be immutable (such as the passing of time) were subjective and shifting phenomena depending on the perceiver.
This provided new insights into suffering. Despite many years of nursing dying people my understanding of the subtle nature of suffering was deepened through this ethnographic practice. Along the journey of the research, I met and engaged with many others who shared similar experiences when adopting ethnographic methods. To these individuals I owe many insights as well as a solid source of support when these new insights undermined and called into question the values and perceptions I had previously taken for granted.

These experiences led me to reflect on ways in which nursing education might benefit from input from anthropological methods and theory, and how this might enable staff to examine and share taken-for-granted practices as individuals and teams in a supported and supportive clinical environment. Integration of

anthropology into nursing curricula has previously been restricted to content relating to transcultural awareness; the valuable methods of anthropology have not been implemented, despite their overlap with many aspects of nursing practice[36].

At present the approach to learning in practice is founded on competencies. Students were required to complete a book of core competencies that includes 'essential skills' to be signed off by their mentors during their time in clinical practice (NMC 2015). The use of competence-based learning is closely related to the agenda for accountability within contemporary clinical governance frameworks (Nehrir *et al.* 2016). Among these were competencies relating to care of the dying, care of older people and maintenance of dignity. Increased emphasis on competency-based practice is also continuing apace within palliative and end-of-life care (Sawkins and Bawn 2010; Frey *et al.* 2011) although there is debate regarding whether it is possible to measure competence in this area.
Over-reliance on nursing competence excludes other kinds of social processes, such as nurses' own histories (Arbon 2004) in which being socialised as a nurse involves an ongoing interaction between experience, interpretation and the objective world. This interaction is what creates individual nurses unique understanding of practice.

Nursing education is not simply a matter of supplying a stock of knowledge from which the nurse can draw, but entails facilitating socialisation into a profession that possesses its own identity, and into which aspects of the nurse's habitus will develop whilst others will recede, in a continuously iterative process. Habitus enables socialisation of nurses to be seen as an embodied process, whereby the nurse draws on a backdrop of experiences and this is placed against existing values. Each one has the capacity to change the other. Habitus can change - this dynamism is crucial and is what enables one to rewrite one's interpretation of a situation.

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[36] *As a nurse educator, I decided to focus specifically upon nurse education. This is not because I believe the nurses to be most in need of education but because I am most familiar with the structures and processes required for current NMC registration (2015).*

Meyer and Land (2005) suggest that learning new ways to think about things engenders a degree of discomfort as it demands progress through a state of dissonance. Becoming a nurse is often described as transformational; it involves rewriting former knowledge, entering a liminal zone and then integrating a new way of thinking and feeling about something. Enabling embodied learning is to nurture a particular nursing praxis (Benner and Tanner 1987). Contextual learning offers learners a kind of practical hermeneutic with which to understand their own and others' practices.

Reflective practice is considered to be a valuable means of increasing self-awareness in complex clinical situations (Thorne 2006; Horton-Deutsch and Sherwood 2008; Allan and Smith 2010). Nairn *et al.* (2012) suggest that learners become adept at understand the *process* of reflection, but not necessarily enabled to understand the underlying complex circumstances that influence their ability to act. Including awareness of the influence of habitus could enable nurses to bring more of their own histories and accumulated capital to bear on understanding the field and the interactions they experience. Wishing to avoid inclusion of Bourdieu's theory as yet another element of the nursing curriculum, this might be better translated into an active form of learning – using Bourdieu's sociology as a form of activism. Theories of habitus can be used to guide students towards reflexivity in practice.

Immersing oneself in the world of another has long been known to provide learning opportunities that are not just intellectual; half of pre-registration nursing hours in the United Kingdom are spent in clinical practice in recognition of the practical nature of nursing. Yet, there is no explicit method for enabling and facilitating the development of emotional insight in to suffering embedded within the curriculum. Indeed, it is almost assumed that simple exposure to patient experience will imbue the individual student with the required attitudes

and sensibilities. This is reinforced by the '6 C's'[37] (Cummings 2012). With no fixed consensus on whether compassion can be taught, and if so the best way in which to go about this, it seems timely to propose an additional inclusion into the nursing curriculum that is directed towards this affective domain of learning. I suggest that nursing education could be enriched by the introduction of anthropological methods to develop insight into the fluid nature of habitus and to actively recruit this process to support nurses' reflexivity. My recommendation is for an additional and complementary approach to nurse education, based upon the methodological approach of this thesis and acknowledging the importance of embodied learning. I suggest that at least one of the pre-registration nursing placements in clinical practice is conducted *without* the use of core competencies. Instead this placement would involve the student taking an anthropological perspective and spending an amount of time engaged in an observer role. Because there would not be sufficient time within the curriculum to get to know a range of anthropological methods, this process could be facilitated by providing the students with a simple observational data tool (see for example Appendix 6). This period of observation could then be followed up by writing of a brief reflection which could be incorporated into their professional portfolios.

Incorporating observational elements to clinical placements is likely to encounter objections from educators and practice coordinators alike. Yet it is precisely because of the busy atmosphere on many hospital wards that such an approach – whilst students are still (at least on paper) supernumerary – may enable the development of insight into patient suffering. Formalising observational approaches by embedding them in clinical practice documentation would provide the required legitimacy to satisfy busy mentors who currently may see this as students not 'pulling their weight'.

[37] These are *compassion, caring, competence, courage, commitment and communication* as outlined in "Compassion in Practice", the response of the Chief Nurse to the Francis Report.

Schon (1987) refers to the difference between reflection-in-action and reflection-on-action. This theory can be applied to the acquisition of emotional intelligence through obtaining holistic understanding of situations. In the usual set up on clinical placements, students are assigned to work alongside or close to a mentor; as well as achieve their competencies there are other expectations, including the fact that they work well as a team member and behave professionally. At the end of the placement they are given a grade. For many years I have heard students tell me that - particularly in busy clinical environments - they are more likely to get a good grade if they immerse themselves in the busyness of the ward and 'pull their weight'. They are often assessed on their usefulness in sharing workload rather than specific nursing attributes contained within their assessment documentation. If the observational placement was not graded but instead the student had an opportunity to feed back his or her findings to the team, there may be additional value as well as numerous transferable skills - not least diplomacy!

Using anthropological observation engages the senses, enabling the use of pre-reflective consciousness in becoming a witness to the suffering patient. Finding oneself in the real environment and exposing oneself to the world of the patient is not the same as reading an account of a patient experience, from the comfort of one's home, on one's computer screen, or in a lecture theatre. It is different too from clinical simulations which are used to try and enable the learner to imagine having poor mobility through wearing cushions under their shoes, or poor vision by wearing opaque glasses. Spending time in the real world provides embodied experience, and these may add to the authenticity and vividity of resultant learning.

When a nurse encounters intangible aspects of human experience such as suffering, for which it becomes necessary to utilise subjective and relational aspects of the nursing toolbox to try to understand something of the experience of the other. This difference can be summed up in a comparison between the 'recording' and the 'perceiving' eye, in which the former gathers information and compares it to existing patterns in order to make a decision or diagnosis. The latter in contrast engages with the fullness of perception (in Merleau Ponty's

sense) and undergoes a gestalt of awareness – that may be pre-reflective – but that nevertheless offers the nurse some insight into what is important to that person. Each individual, exposed to the same set of circumstances and environmental stimuli, will respond in a different way. This is based on their own habitus - part of which may be shared as a member of a group (for example, as a staff nurse) but part of which will be uniquely related to an individual's biography. As such it is the unique response to circumstances that can formulate exactly what it is that the nurse responds to in a given set of circumstances, what constitutes suffering, and so on.

Observational methods for peer review

There is no reason that observational methods need to be restricted to nursing education. Such an approach could be used in clinical practice for qualified health and social care professionals, whereby staff are afforded a clearly bounded supernumerary status to spend time observing and documenting the experiences of patients and then feeding this back to their colleagues. The idea of peer review is not new, and there are an increasing number of novel ways in which individuals are supported to reflect on their own and their colleagues' practice (see for example Goodrich 2011; The Kings Fund 2011). Observational approaches have also been used to help staff to understand patient experience in context. A key example of this is in work around Dementia Care Mapping (Brooker 2005) although the majority of existing evaluation of this process relates to its impact on staff wellbeing rather than on issues around the observer and the impact of their own positionality on what they subjectively perceive in the person with dementia.

Observational methods could be used for personal professional development, and the feedback process from this experience could be drawn upon to inform learning and feed into ongoing service improvement. This would serve to illuminate more subtle aspects of patient experience, as well as limit the amount of top-down regulation and monitoring. Observing patients is already established in other clinical and allied professional training, for example the psychodynamic training at the Tavistock Institute (The Tavistock and Portman NHS Foundation Trust 2016) yet is under-explored in the more conventional clinical professions such as nursing and medicine. The aim of utilising

observational methods as part of broader education (and socialisation) into nursing practice is to enable some new perspectives from the nurses who are ideally placed to be activists and advocates within the clinical setting.

Staff could subsequently write a reflective piece based on their experiences of observation. For students, this could be integrated into the development of their portfolio required for registration with the NMC. For qualified nurses, such reflections could be included in the revalidation portfolio, as required since the changes in professional re-registration in the aftermath of the Francis Report (NMC 2015; 2015a).

Of course, awareness of the limitations of power dynamics and the inhibitory impact of regulation will not suddenly liberate nurses to provide the care that they wish to, but the self-reference that results from reflexivity is an important step towards practice change. Individuals cannot easily transcend the social constructs that have led to their particular habitus and their stock of symbolic capital, but Bourdieu's analysis challenges the structuralist notion that we are entirely at the mercy of our conditioning, and opens up the possibility for social change that results from reflexivity. This leads to my next suggestion which relates more directly to interactions between professionals in the context of acute hospital care.

10.3.2 Mapping ideologies to specialisms

As already discussed, there are strong arguments in the literature over the last twenty years for the integration of palliative care into the hospital setting, both in the UK (Gardiner *et al.* 2011; Gott *et al.* 2013) and internationally (Pincombe *et al.* 2003; Bloomer *et al.* 2011; 2013) which is increasingly being translated into policies to guide practice (Thomas 2010; NHS England 2014; Department of Health 2015). But there continue to be examples of care that is lacking in compassion, particularly for older people at the end of life. The case has also been made for geriatric medicine and palliative medicine to work more closely together, as it has been suggested that each discipline can learn from the other in important ways that are likely to benefit the patient (Patterson *et al.* 2014, Albers *et al.* 2016). However, little has been written on the relationship between older person's medicine and palliative care in the context of acute care and on the complex interplay between these three approaches.

Ethical decision-making

In 1978 Anselm Strauss described his popular theory of the 'negotiated order' of the hospital and demonstrated its influence on care (Strauss 1978; Degeling and Maxwell 2004). This remains the case; nurses continue to be attached to the ward and its routines, and to possess knowledge of patients and their families to which the medical staff are not privy. The physicians' alliance is with the hospital more broadly; they work across several wards and are involved in teaching medical students within their specialisms. Strauss suggested that as such the hospital is merely a geographical site where different professions converge to carry out their work and although they may refer explicitly to holding a shared purpose of patient-centred care, this is frequently interpreted in diverse ways by the various individuals according to their identities. This apparent shared purpose masks a range of conflicts, and some of these have been described in this thesis. One of the key loci for conflict relates to decisions that need to be made when a person may be approaching the end of life, when they are no longer responding to active treatment or where such treatment is unacceptably burdensome. Such decisions are frequently ethically fraught, and

whilst moral frameworks such as Beauchamp and Childress principals (2008) can aid decision-making, these do not take into consideration subtle interpersonal processes such as power. Such approaches also presuppose a level of self-awareness regarding the nature of the 'right' thing to do in a context that is free from one's own values, and free from the powerful forces of regulation and risk-aversion in practice. It is misleading to suggest that adopting ethical decision-making frameworks mitigates against subjectivism

Approaches to improving compassionate care mean attending to personhood: what was the most appropriate goal of care for this person, at that particular point in their journey? How might the team have collectively and collaboratively avoided causing or worsening suffering? Particularly where patients lacked capacity to engage in this discussion and not have indicated any preferences, the difficulty of such decision could have been mitigated by attending to the context in which such decisions took place. The route to minimising patient suffering may not be obvious, particularly if it is at odds with the safety agenda. In some cases, the right thing was professionally counter-intuitive and yet in certain situations, the right thing may end up being the least harmful thing.

Interprofessional disagreements regarding the most appropriate care are common, as evidenced both in this PhD study and within the broader literature. Many of the tensions described in chapter 5 spoke to the differences in capital between professionals involved in care, and loosely associated approaches to care with ideological positions and historical developments of clinical specialties. Agents in the field possessed different amounts of capital which were strongly related to their professional identity. Those with most capital were more likely to have their position adhered to by other players in the field, as this capital conferred on them a greater degree of power. This then informed actions taken in relation to care. Some clinical decisions were made not because they were medically or ethically 'right', but because the ultimate decision in the context of a multidisciplinary team discussion was a product of historical differences in capital possessed by the different members of the team. Furthermore, as shown in chapter 9, such actions could be constitutive of harm and could cause or exacerbate suffering in patients who were already

experiencing multiple obstacles to wellbeing. Adopting a particular approach to care could cause or increase suffering if it is informed by adherence to ideologies rather than patient-centred. I suggested in chapter 5 that over and above the social and cultural capital of the different healthcare professions there was a more powerful and diffuse source of capital in the form of managerial structures and regulatory bodies and that these often ultimately dictated the direction of care.

An example of these kinds of difficult decisions is the identification of those patients who are at the end of life. As already described, at the beginning of this study when I spoke to the clinical team to identify which of the current patients they considered might be in the last months of life, I was told *"none of them"*. This was in spite of evidence that a significant proportion of hospital in-patients are likely to be in the last year of life, among these the majority are older people in acute wards (Clark *et al.* 2014). Of the eleven patients whose stories have been told in this thesis, all died within four months of my completing the fieldwork, most in the ward but three in other settings. As the implications of this attitude became clearer, I saw many ways in which treatment was offered or continued beyond the point of utility, and the implications that this had not only on patients but on their families and staff. This observation is not new and is an ongoing concern in the palliative care literature. Hospital deaths are so closely associated with adverse incidents that death continues to be seen as a failure of the system even where the person who has died had multiple chronic and life-limiting conditions and death was predictable. Where death was predicted, this tended to be very close to the point of death, despite it being well established that early identification of deterioration can help to prepare patients and their loved ones, plan appropriate treatment, avoid iatrogenesis and facilitate transferral to the most appropriate place of death with adequate funding in place. This denial of patients being at the end of life has been explored in chapter 5 as the problematisation of the 'rescue' ideology, and is particularly problematic in the context of patients who have multiple comorbidities such that no clear prognostic indicators are available to facilitate clinicians to make such predictions.

Many existing suggestions in the literature for improving teamwork focus on training in interpersonal skills and collaborative working or focusing energy on developing rapport within the team. Other innovations such as Schwartz Rounds (Goodrich 2011) appear to help members of the team gain insight into the particular pressures and demands of other roles and enable mutual understanding so that members of the team can work towards shared goals with patients. However, these interventions lack an evidence base and there are structural barriers to their use on busy acute wards, primarily staff time and the opportunity to release key staff from duties. Yet multidisciplinary meetings happen regardless of how busy the ward is – they are embedded in the hospital routine and protected by policy – so there may be opportunities to consider how this existing structure might be utilised.

Multidisciplinary meetings: current format

Hospital teams in acute hospitals in the UK are expected to hold weekly multidisciplinary team (MDT) meetings to discuss issues such as investigations, treatments and communications. The Francis Report identified that the effectiveness of multidisciplinary working is a powerful influence on the development of shared plans of care. They cite from a current best practice document:

> *"[Medical ward rounds] provide an opportunity for the multidisciplinary team to come together to review a patient's condition and develop a coordinated plan of care, while facilitating full engagement of the patient and/or carers in making shared decisions about care. Additionally, ward rounds offer great opportunities for effective communication, information sharing and joint learning through active participation of all members of the multidisciplinary team" (Varo et al. 2012, p1)*

A ward round is a complex process of reviewing clinical care, and entails reviewing progress against the anticipated trajectory on the basis of history and other information. It is the place where decisions are made regarding future

care, and where plans for communicating this to the patient and their loved ones are clarified.

Crucially, the MDT was perhaps the main opportunity to identify when a patient may be at risk of iatrogenesis and the potential place where decisions to pursue inappropriate interventions can be challenged. And yet there is still evidence that this does not happen, and the ideology of rescue is prioritised right until the last moment, with many dying patients not identified until the last hours of life. The MDT meeting offers a unique opportunity for intervention to minimise iatrogenesis. The current RCP / RCN guidance does not mention potential conflicts in care goals, nor does it mention decisions needing to be made regarding palliative or end of life care or of the need to withdraw or withhold treatments.

The invisibility of end-of-life care in MDT discussions means there was no prompt to encourage staff to question the legitimacy and appropriateness of the interventions they were discussing. Although ‘ceilings of care’ were considered, these were not explicitly framed in terms of the patient reaching a point in their illness trajectory at which their disease was no longer amenable to curative intervention. When the needs of dying people are considered it is important to obtain detailed pictures of what these needs are throughout the dying trajectory, not just in the last days of life.

This study identified that staff felt there were often multiple foci (which sometimes conflict) for team meetings: enabling them to be discharged was a primary goal, providing high quality safe care and a satisfactory clinical outcome was considered secondary to this. Some goals were associated with individuals’ specific profession, for example nurses in the study would refer to goals relating to medication and continence, occupational therapists specified particular tasks or activities, and so on.

One way to change this current practice in order to open up a space for acknowledgement of the complexity of the kinds of patients cared for in such clinical settings would be to create a guiding structure for multidisciplinary ward

meetings. The present format for such meetings focused on the immediate tasks in hand relating to each individual patient. Decisions were informed by pathology results, professional opinions, family meetings and a range of other sources of information. Ultimately the accountability fell to the doctor in charge and the decisions related to avoiding risk and expediting discharge. A key element often missing from these discussions was an agreement about the overall goal of care for each patient (Baxter and Brumfitt 2008).

Redesigning Multidisciplinary Discussions

Two key elements frequently missing from MDT discussions that have been identified within this thesis as significant in impacting on suffering. The first is an opportunity to identify conflicting and contrasting goals of care, and the second is to agree when the efforts informed by one goal of care is no longer effective and a change in gear is indicated. Existing guidance in acute care relating to end of life care focuses upon care in the last few days of life. However, only one of the participants in this study fitted into this category – the rest were in the last weeks or months of their lives, as evidenced by the fact that every one of them had died within five months of the completion of the study, and yet none of them had been identified as ‘end of life’. Their journeys may have been very different had the MDT been agreed that they may be approaching the end of life.

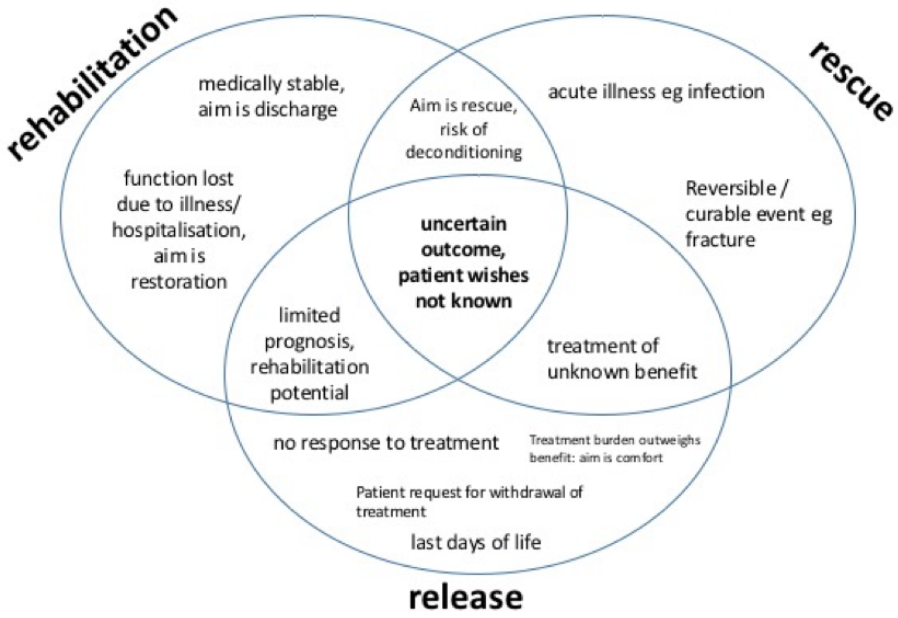
A structured approach to MDT discussions may make it possible for staff to acknowledge the personal impact of dealing with ambiguity and negotiating conflicting pressures, as a means of tackling the negative sequelae of moral distress in clinical practice. By refocusing team discussions on to the goals of care (rather than engage in discussions that emphasise professional conflict, draw on power, or highlight risk) the team may achieve a greater degree of cohesion and converge upon goals of care.

The ideologies identified in chapter 5 could inform broad categories that dictate an overall approach to care, whilst acknowledging the complexity and likelihood of change that is common during the trajectory of a person’s hospital stay. Although rarely the case that patients adhere neatly to one picture or the other, there is nevertheless usually a primary goal that dictates care. A patient who is

suitable for rehabilitation can be identified as such during the MDT, and at the same time any unnecessary investigations can be discontinued. If the team were prompted to firstly agree on the current goal of care (with acknowledgement that this could change at any point) then subsequent decisions might be felt to be more coherent. For example, if a patient is felt by the team to be suitable for rescue, then decisions relating to their care can focus upon this goal and discussions of discharge can take a backstage position for the time being. If, however, a patient is deemed to be medically stable and for a rehabilitative approach, then the utility of continuing blood tests and other investigations ought to be questioned and the focus of clinical effort should be upon maximising independence and facilitating discharge to their chosen place of care. Finally, if the team agree that a patient may be dying, it is reasonable for them to have a discussion about what interventions remain valuable, who might be best placed to talk with their families, and whether moving them home or to another place of care is possible or desirable. Focusing the discussion on the goal of care rather than defaulting to dominant ideological positions may enable the team to question their approaches and to ensure that their focus remains patient-centred.

The dominant ideology frequently dictates the focus of care even where there is evidence to contradict the argument that this is the most appropriate approach for a particular patient. The image below illustrates one example in which the broad framework relating to the ideologies can help to guide discussions about the goals of care. By way of example, three treatment choices have been superimposed on to the image to demonstrate how they can be seen as appropriate in one part of the model but would be possibly inappropriate elsewhere. Enteral feeding for a person considered to be at the end of life is one example of this. The schematic diagram (Fig 16) is not intended to be instructive but illustrative of the way in which clarifying the overall goal of care can naturally lead to ethical clarity about the right thing to do.

Figure 16: Goals of care



This structure not only includes objective clinical data but also patient preferences such as a wish to discontinue treatment, or a perception of burdensome interventions. Such information may be derived from the patient, their families, or from staff who know the patient well. One of the findings of my study has been a remarkable lack of involvement of family members in the ongoing provision of care. Their involvement came into play when critical decisions needed to be made (such as withdrawing treatment, as in Ellen's situation, or commencing on a syringe driver, as with Paul). However, in terms of the overall goals of care, there was little indication about what the patient or their families considered to be in their long-term interest in the wider context of their lives outside the ward. Incorporating wider perspectives of patients and families into this decision-making process

One potential objection to this is the time that would be taken to gather these perspectives, coupled with a concern that families are not clinically trained. However, they were already being asked to make decisions when situations become emotionally fraught – a much more difficult process – so although this would be something of a cultural shift, it would potentially facilitate decision-making in those overlapping areas between ideological approaches. Some patients and families will want everything doing, others will want to be left alone and for nature to take its course. Some will prioritise being at home over

accurate diagnosis of clinical conditions, while others will find the hospital environment reassuring and comforting. Utilising patient and family preferences in this way in the MDT meeting need not be tokenistic, nor should it form a vague background context against an overall medicalised decision-making pathway. It has the potential to enhance understanding about elements relating to each individual patient that can impact on the processes and outcomes.

The areas of overlap of all three domains is the area where iatrogenesis is a risk. Here, the team can be prompted to identify whether there are any additional sources of information or insight that might nudge the direction of care in one direction or the other, for example a discussion with the patient and/or their family may be scheduled, or a nurse who knows the patient particularly well might be asked for their professional opinion.

MDT discussions could be guided not by each professional taking it in turn to offer their opinion on a particular patient, but by a facilitator asking at the outset what the agreed priority of care is for that patient at that time, and then reviewing – having heard the evidence from the different professionals present – whether this is still felt to be appropriate. Exploring whether this might work would involve the development of a decision-making tool, ideally in collaboration with patients and families, that would then be piloted in an MDT context to see if it was found to be helpful in clarifying goals of care. One method of evaluating such an intervention would be to document changes of direction that result from MDT discussion, as well as to record all instances of treatments felt to be inappropriate or futile.

Acknowledging uncertainty

Healthcare professionals face a range of uncertainties during their education and subsequent socialisation into practice. Much of this relates to what has been described as a growing sense of awareness of the limitations of personal and professional knowledge (Fox 1980) or for nurses, an increasing sense of the ethical dimensions of clinical practice in an ever-more medicalised healthcare environment (Weaver *et al.* 2008; Van Der Zande *et al.* 2014). It has been suggested that clinical uncertainty can cause ambivalence and lead to

professionals demonstrating increased tendencies towards goal-orientated approaches to care (Timmermans and Angell 2001; Spafford *et al.* 2007) in which ambiguous elements of the clinical scenario are treated as problems.

The real-world context of uncertainty is what has recently prompted development of the Amber Care Bundle, a planning and decision-making tool that recognises the complexity of treatment planning in cases of uncertain prognosis such as haematological malignancies (Etkind *et al.* 2014; Bristowe *et al.* 2015; Carey *et al.* 2015) although perhaps unsurprisingly, research into the utility of the tool has slowed since the withdrawal of the Liverpool Care Pathway and the resultant ambivalence around tools to aid end-of-life care decision-making. The schematic diagram above could be used as the foundation for the development of a decision-making tool aimed at use during MDT discussions, one that recognises clinical uncertainty and enables the focus of discussion to be guided by the overall goal of avoiding inflicting suffering, rather than the all-too-common default goal of patient safety and risk-avoidance. The schematic goals of care diagram recognises clinical uncertainty and may offer guidance to avoid iatrogenic suffering. Future research could explore implementation of these innovations, drawing on a broad range of approaches to evaluation to examine their impact on staff attitudes and interprofessional working, diversion of potentially iatrogenic interventions and recreation of potentially iatrogenic environments.

10.4 Final Reflections

Reflections on the Francis Report: safety and compassion

During the fieldwork, the Francis Report was mentioned several times. The matron informed me that she was usually quick to approve requests for additional staffing *"on the back of Francis"* because *"it needs to fit in with RCN recommendations"*. But whilst the dominant message in the Francis Report is one of enhancing patient safety (the word 'safety' appears over 300 times in Part 3 of the report) whilst recommendations around compassion are slightly less clear ('compassion' appears 33 times). The primary message of the Francis Report centres upon patient safety. Many recent changes in practice reflect this,

as do such attitudes as the Matron's interpretation that "*it is all about the safety"*. Yet the Inquiry was initiated because of a group of relatives who were unhappy about the ways in which their loved ones died, the lack of communication they received and the dismissive way in which they felt treated. The inquiry was catalysed when these relatives approached the media with their stories; and the stories were tales of suffering and lack of compassion within the system, not explicitly about safety. It is the subsequent analysis and interpretation that safety has been foregrounded to this extent.

My first reflection regarding the Francis Report relates to this overarching focus on safety – whilst evidently a vital component of a healthcare system that cares for people at vulnerable times of their lives - inadvertently omits the needs of the people who were most at risk of poor care. This thesis has demonstrated that often, patient suffering can go unnoticed in the busy environment of the hospital ward. Further, by attending to inspections, incidents and complaints as the primary sources of data on the quality of care means that the kinds of suffering described in these pages can easily go unseen. Recommendations for medical training again focuses primarily on team leadership, patient safety and other aspects of quality (but does not explicitly mention compassion, or ethical decision-making. This implies that compassion is solely the domain of the nursing staff, who are advised to spend three months working in direct patient care prior to entry into nursing training, evidence their compassion and care through a learning portfolio, and systematise contact with patients through regular ward rounds. The fundamental standards of behaviour were to be built into job descriptions and values-based recruitment for attributes including integrity, empathy, resilience, team-working and situational judgment tests.

A further reflection is the assumption as to the nature of culture. Changing culture is addressed within the report's 290 recommendations through two main avenues: managerial structures, and individual responsibility. Whilst the report claimed to have identified that a key concern in Mid Staffordshire was the fact that there was a *"culture focused on doing the system's business – not that of the patients"* (Francis 2013b, p4) it appears that many of their recommendations risk perpetuating this practice through a failure to address the complexity of

healthcare culture. An emphasis of the report is upon changing to a 'common' healthcare culture to one which is more compassionate, and in which each individual shares the goal of putting the patient first. However, there is little explanation of what constitutes a culture, nor of the existence of multiple cultures and subcultures that constitute the field of care that I observed in this study. Assumptions as to the existence of a singular, cohesive culture presupposes that individuals possess equivalent agency when it comes to creating and sustaining compassionate environments of care. I have shown that different professionals possess different degrees of agency in different context and certain actions were much more readily permitted if they fit within the overall ideological approach of the ward. Even though the stated goal of the report was to transcend previously existing 'cultures of fear' that arose through individuals feeling beholden to achieving targets, the new recommendations simply provided a new set of targets, albeit more explicitly focused on patient-centred care, but which did not address the core issue of staff feeling under pressure from regulatory processes.

The most recent review of nursing in the aftermath of the Francis Report proposed that nurses adhere to six core values and that (in conjunction with the professional code of nursing ethics) would provide guidance at difficult times. This thesis has argued that regardless of the ethical imperative of nursing, the dominant policy directive with regards to patient-centred care, and the national publicity relating to compassionate care, there are forces at work in this institutional setting which had far more influence on daily practices than any external guidance or directive. To this end, enhancing the quality of person-centred care needs to focus upon making this internal reality apparent to those outside. The field of the ward, the doxa and habitus of practitioners and the comparative jostling for capital that takes place between social groups in these overlapping fields all influence patient experience.

Practical compassion often involves a person doing something to another person. A report on the progress of the 6C's campaign in nursing highlighted through the use of numerous quotes and case examples the 'little things' (Smith 2008) that nurses often feel constitute compassionate care - rearranging pillows

to facilitate comfort, providing a drink, personalising a care plan and the like (NHS England / Nursing Directorate 2013). However, this restricts the notion to the purely visible aspects of compassion and speaks to the broader political imperative of encouraging aspects of care that can be measured, under the broader umbrella of clinical governance (Department of Health 2015). Simply feeling for another person's experience (usually conceptualised as empathy) is insufficient for the current institutional requirements of care. Also required are the skills to recognise a range of manifestations of suffering, and the empowerment and interprofessional insight required to challenge situations in which organisational, cultural or institutional priorities take precedence over patient-centred ones. Finally, unless staff feel themselves to be working in a compassionate environment themselves, then it appears less likely that they will be enabled to recognise and act on the suffering of their patients. The risks of compassion fatigue and burnout are extensively addressed within the literature and the sheer volume of exposure to suffering as happens in this kind of healthcare environment can have a deleterious impact on the emotional wellbeing of staff unless they themselves feel supported (Sabo 2006; Slocum-Gori *et al.* 2013).

Reflections on observational research

The methods used in this study required an arduous process of ethical approval which I reflected upon in chapter 3. It is worth revisiting this to reflect upon how we might learn from what has been discovered about the risks and benefits of using observational methods in this way. The risks highlighted by the panel related to the vulnerability of patients to distress and indignity, and the potential for the terminology of the study to cause concern for patients. Potential benefits of the study were not really a consideration during the ethical approval process. In retrospect, benefits of such studies could feature more prominently in consideration of providing balanced ethical opinions. Benefits could be identified for both staff and patients, as well as for myself. For staff, my presence on the ward - whilst occasionally challenging and uncomfortable - offered opportunities to reflect out loud about a range of difficult ethical situations, such as when the dietician wished to discuss the issue of feeding tubes for people with dementia,

or where a new registrar commented that *"we never usually think about this kind of stuff"* after we talked about the study over lunch one day.

A further benefit related to staff perceptions of wider opinion relating to the nature of the work that they did. There were many examples where staff made a point of telling me about their shift or about particularly difficult experiences, this was sometimes appended by a comment about what 'they' think geriatric nursing or medicine actually involves. It was not always clear who 'they' might be; it might refer to hospital management seeing the ward as a 'Cinderella service' (Kydd and Wild 2013) or to relatives who express concerns about poor care based on opinion received via the media, or to clinical staff working in other more acute and more popular areas. For patients, benefits were varied. It was clear that some found my presence a break from solitude, particularly those who were in side-rooms. The majority of informal conversations which have formed the bulk of the raw data were initiated by patients, not prompted by myself. Talking sometimes seemed to enable venting of difficult emotions.

Research into the potential benefits of participation in observational studies is sparse but might provide useful supporting information for researcher wishing to undertake similar studies in the future. I have already discussed the importance of inclusion of vulnerable populations in the research literature, in order to ensure that their voices (or proxy) are considered in the development of policy - particularly as they form the majority of people who are affected by the kinds of issues raised in investigative reports that follow complaints about poor care. This would address the imbalance in the research literature that sees the bulk of research on suffering at the end of life as being conducted through interviews and surveys with relatively well and cognisant participants. The most vulnerable patients who are at greatest risk of being affected by issues relating to care are the least likely to participate in such studies. As such there is an ethical imperative towards inclusivity and representativeness.

10.5 Conclusion

This thesis has drawn a picture of events taking place over a single summer on a single ward in a UK hospital, drawing on the experiences of eleven key

patients. Although findings are not generalisable, the analysis has added to our understanding of the experiences of dying or acutely unwell older people in hospital. An account of suffering experiences has been presented, alongside perspectives of those responsible for diagnosing, treating and caring for those people. Clinical practice has been located within social, cultural, political and philosophical contexts, drawing on Bourdieu to view these worlds in a relational rather than a structural way.

Compassion is both relational and contextual. Whilst not wishing to demean interventions such as communication skills training, transactional leadership, and ward-based practice-developments that focus on patient-centredness, I suggest that we might also consider helping healthcare professionals become reflexively aware of the complexities of the culture of the healthcare environment, the subtle and easy-to-ignore manifestations of suffering in older people, and their own ideologically informed preferences for care through drawing on Bourdieu's theoretical perspectives regarding social action. The purpose of adopting these theories has been to engage in the task of uncovering some of the hidden workings of habitus, which for Bourdieu constitutes a form of sociological analysis that offered insight into why things were the way they were, particularly in relation to the place of social actors in the society in which they exist. This has been useful both in terms of the health and social care professionals who occupy distinct but overlapping fields within the hospital. It has also suggested some explanations for the kinds of responses to suffering that were observed in the participants, as well as insight into why these responses varied so widely and why this is an important finding for understanding why recognising suffering is not as simple as diagnosing a physiological dysfunction.

My recommendations are aimed at making changes to practice that might enable an approach to care that prioritises the actual or potential suffering of the patient. The majority of suffering was psychosocial and embodied in nature, rarely relating directly to physical aspects of their conditions but almost always associated with existential aspects of experience. This is a key finding and challenges existing assumptions in the healthcare literature about the

predominance of concerns about symptoms for people in the last months of life. Much suffering was found to be iatrogenic, whether via interactions with staff, clinical interventions, or the environment. There are numerous ways in which this kind of suffering could be addressed with simple interventions.

Cassell's work continues to impress upon generations of clinicians the need for a refocusing upon personhood within the practice of medicine. And yet four decades on there is still no sign that medicine is any closer to addressing the roots of human suffering, as attested to by the narratives within this thesis as well as countless other first-person accounts and research studies. One reason for this is that the central thrust of Cassell's argument is a humanitarian one; he urges doctors to focus upon the person in front of them and to consider the therapeutic role of medicine as strengthening of this relationship. But his argument does not take into consideration the limiting impact of the wider healthcare environment, constituted as it is of public expectations, institutional requirements, and broader political pressures. These have been shown repeatedly to exert strong pressure on clinicians that can inhibit any natural inclination towards person-centred care.

Returning to the first aspect of my definition of compassion in chapter 1 - the ability to recognise suffering – chapters 6 and 7 illuminated some of the complexity of the concept and described ways in which suffering remains inchoate, despite efforts to quantify, reduce and theorise. These chapters lead to a critique regarding the extent to which the stated goal of palliative care - recognition and alleviation of suffering - can be achieved in the ward environment. chapter 8 examined theoretical aspects of suffering to illustrate the porosity of theoretical perspectives on suffering between disciplines. These chapters led me to suggest that recognising suffering is not a simple process and that compassion may be thwarted right at the beginning of the process simply by virtue of the fact that the manifestation of suffering is too subtle, too complex, too intangible for staff to identify it clearly as a problem in need of addressing.

The second part of the definition – motivation to alleviate suffering – has been addressed by examining ways in which suffering does not belong to any one professional domain, and as such remains in peripheral vision as physical clinical problems are preferentially addressed. chapter 5 explored a range of competing pressures that shape staff priorities including regulatory requirements, patient safety needs, and the ubiquitous pressure on hospital beds necessitating rapid throughput of patients with little time to get to know them. Chapter 9 also addressed this issue by considering the phenomenon of iatrogenic suffering, and describing ways in which some of the practices that contributed to patient suffering were generated by the interactions, interventions and environment of the hospital but because they were constitutive of habitus they were largely pre-reflective; staff were not always aware of the suffering being caused by the well-intentioned actions of care.

The final part of the definition – having the resources to act – was explored in chapter 5 through adopting Bourdieu's concepts in order to illustrate that staff may not always possess the necessary capital to enable them to bring about particular compassionate actions. Professional differences in social and cultural capital have led to individual staff members lacking the required power to step outside the taken-for-granted way of doing things that is dictated by management, and to a lesser extent by the leading clinicians. Even where suffering is recognised and where staff have sufficient time and motivation to act they may still fail to do so on account of these forces. The overarching dominance of social and symbolic capital contained within the practices of hospital management structures inhibited any activity that was not explicitly directed towards explicit goals of these higher structures. Institutional and organisational forces have created and reinforced a culture of compliance. Staff members were under surveillance to such a degree that it became embodied and transformed into self-surveillance. This has created a set of priorities that focus upon efficiency and safety, and providing compassionate care is often placed in opposition, or at a lower level of priority, to these requirements.

As long as hospitals are driven by economic and bureaucratic goals, and the lesser goal of compassionate care remains rhetorical rather than fundamental,

suffering will continue to go unrecognised in this and similar environments of care. Suffering is a part of the human condition, particularly when a person is approaching the end of their life. The palliative care goal of alleviating suffering at this time is admirable but (I would suggest) unachievable. A more realistic goal might be to understand that suffering is present and often unavoidable, and to seek to identify any potential for iatrogenesis that can cause or compound suffering. Central to this is understanding the difference between unavoidable suffering, suffering that is amenable to intervention, and suffering that is a consequence of care. Compassion requires that a patient's suffering is recognised and that there are sufficient resources to respond appropriately. This is an ethical and a moral activity, not a bureaucratic one. A market-led healthcare system requires a profound change of direction if care is indeed to become more compassionate. In some small way, I hope that this thesis can contribute to change needed to protect older people's quality of life in the last precious weeks and months of life. For those of us with the honour and privilege of witnessing those final months, I hope that the stories herein will act as a reminder of the humanistic imperative of care.

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Appendix 1 – HRA and R&D Ethical Approval

NRES Committee Yorkshire & The Humber - Leeds West
Room 001, Jarrow Business Centre
Rolling Mill Road
Jarrow
Tyne and Wear
NE32 3DT

Telephone: 0191 428 3387

27 November 2014

Mrs Laura Middleton-Green
PhD Candidate, Lecturer in palliative and end-of-life care
University of Bradford
Division of Nursing, School of Health Studies
Richmond Road
Bradford
West Yorkshire
BD3 9LE

Dear Mrs Middleton-Green

Study Title:	**A qualitative exploration of healthcare professionals' recognition of suffering in patients at the end of life in the acute hospital setting**
REC reference:	**14/YH/1208**
IRAS project ID:	**149773**

The Research Ethics Committee reviewed the above application at the meeting held on 14 November 2014. Thank you for attending to discuss the application.

Provisional opinion

The Committee would be content to give a favourable ethical opinion of the research, subject to receiving a complete response to the request for further information set out below.

Authority to consider your response and to confirm the Committee's final opinion has been delegated to a meeting of the Sub-Committee of the REC consisting of Dr Sheila Fisher, Dr Jane Orton and Ms Sarah Kirkland.

Further information or clarification required

1. Submission of any peer reviews which have been undertaken for this study.

2. Clarification regarding whether private behaviours and care undertaken behind a curtain, for example, would be observed or not. If they would be, a simple consent form for patients and visitors to consent to this (or consultees to give advice if a patient lacks capacity) should be submitted.

3. Clarification regarding who would transcribe the interviews.

4. Submission of the posters and leaflets to be used in this study.

NRES Committee Yorkshire & The Humber - Leeds West
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30 January 2015

Mrs Laura Middleton-Green
PhD Candidate, Lecturer in palliative and end-of-life care
Division of Nursing, School of Health Studies
University of Bradford
Richmond Road
Bradford
West Yorks
BD3 9LE

Dear Mrs Middleton-Green

Study title:	**A qualitative exploration of healthcare professionals' recognition of suffering in patients at the end of life in the acute hospital setting**
REC reference:	**14/YH/1208**
IRAS project ID:	**149773**

Thank you for your letter of 26 January 2015, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Miss Sarah Grimshaw, nrescommittee.yorkandhumber-leedswest@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Mental Capacity Act 2005

I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005. The committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

NHS
Health Research Authority
Yorkshire & The Humber - Leeds West Research Ethics Committee
Room 001, Jarrow Business Centre
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Tel: 0207 104 8087

12 July 2016

Mrs Laura Middleton-Green
PhD Candidate, Lecturer in palliative and end-of-life care
University of Bradford
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Dear Mrs Middleton-Green

Study title:	**A qualitative exploration of healthcare professionals' recognition of suffering in patients at the end of life in the acute hospital setting**
REC reference:	**14/YH/1208**
Amendment number:	**SA02**
Amendment date:	**27 May 2016**
IRAS project ID:	**149773**

The above amendment was reviewed by the Sub-Committee in correspondence.

Summary of amendment

This amendment was submitted to seek approval for the use of photographs within the student's thesis. Photographs would not contain any identifiable information.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

The Sub-Committee queried how the presence of a person with a camera in a care environment would be managed to ensure that patients and relatives did not feel uncomfortable.

Ms Laura Middleton-Green, Chief Investigator, confirmed that he photographs would be retrospective - the environment had not changed since the study and since none of the photographs would be of people, she believed they would still be of use in the project. For example, Ms Middleton-Green stated that the design of the ward was found to strongly

[redacted] NHS

NHS Foundation Trust

[redacted]

01 August 2016

Ms Laura Middleton-Green
School of Nursing
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University of Bradford
Richmond Road
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Dear Ms Middleton-Green,

ID: **1211** **A qualitative exploration of healthcare professionals' recognition of non physical needs in patients at the end of life in the acute hospital setting**

IRAS ID: **149773**

Protocol amendment No: **SA02**

The amendment has been assessed against HRA standards relating to the legal and regulatory aspects of the study which confirms that these standards have been met, including all applicable regulatory approvals. The following documents relating to this amendment have been reviewed:

Document	Version	Dated
Email Notification of Amendment		17 June 2016
HRA REC Valid Amendment Letter		17 June 2016
HRA REC Favourable Opinion Letter		12 July 2016

The photographic images taken for this phase of your research must be approved by the senior nurse team on the Ward prior to use in any publication.

Our Trust follows the HRA process for study amendments and the sponsor maintains the responsibility to inform our site of any changes to the study. The study will continue to be required to comply with our audit and monitoring procedures for research.

NHS
Health Research Authority

Yorkshire & The Humber - Leeds West Research Ethics Committee
Jarrow Business Centre
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Tel: 0207 104 8117

28 July 2017

Mrs Laura Middleton-Green
PhD Candidate, Lecturer in palliative and end-of-life care
Division of Nursing, School of Health Studies
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Dear Mrs Middleton-Green

Study Title:	**A qualitative exploration of healthcare professionals' recognition of suffering in patients at the end of life in the acute hospital setting**
REC reference:	**14/YH/1208**
IRAS project ID:	**149773**

Thank you for sending the progress report for the above study dated 15 March 2017. The report will be reviewed by the Chair of the Research Ethics Committee, and I will let you know if any further information is requested.

The favourable ethical opinion for the study continues to apply for the duration of the research as agreed by the REC.

14/YH/1208:	**Please quote this number on all correspondence**

Yours sincerely

Rheanneon Fuller
REC Assistant

E-mail: nrescommittee.yorkandhumber-leedswest@nhs.net

Copy to: *Ms Jennifer Bellamy, University of Bradford*
Mr Lesley Argyle, Huddersfield Royal Infirmary

Appendix 2 - Ethics: A Reflection

In this appendix I consider the primary concerns raised by the ethics panel. I will then discuss two situations that arose in the course of the fieldwork. Through an exploration of the ethical issues that they invoked, I argue that the current structure and format of the Research Ethics Committee approval process, whilst offering important safeguards for vulnerable research participants, does not attend to the situated ethical dilemmas that arise in the day-to-day practice of observational research. Indeed, such bureaucratic processes often present serious obstacles to undertaking research with, on and for the most vulnerable members of our society. By offering an insight into the daily practice of undertaking observational research in clinical settings, this paper offers a researcher's perspective on situated ethics in the hope that it may serve to education REC panel members regarding the subtle nuances of observational research.

The ethical concerns expressed by the panel related to three key points; (1) the protection of participants likely to lose capacity to consent to be observed (2) the use of the word 'suffering' which was considered to be inappropriate (the panel requested that it be replaced with the term "non-physical distress") (3) whether or not the study would be able to achieve its aims through observing less vulnerable participants. I argue that abstract research ethics standards as regulated by the United Kingdom's Research Ethics Committees (RECs) offer little support with regards to the everyday ethical and moral dilemmas arising during the course of the study.

Suffering was a problematic word for the panel. They voiced concern that it was a leading term, poorly-defined, and perhaps more poorly understood. I attempted to explain that this was precisely the reason for choosing to research it, yet the panel insisted on the use of clearer terms. Their suggestion was that all participant documentation be amended to state the object of research as "non-physical distress". When I was explaining the study I readily used the word 'suffering' with both staff and patients/relatives. I did not perceive any instance of the use of the word itself as causing suffering. I was asked several times for clarification of what was meant by "non-physical needs", to which I

responded that it was a “bit like suffering”. The latter was more readily understood.

Concerns regarding day-today ethical decision-making were not voiced by the panel. The REC was satisfied by my explanation that I would intervene in a clinical situation if there was a risk of harm, in accordance with the professional code of conduct to which I adhere. They referred to my clinical experience as a palliative care clinical nurse specialist as adequate assurance that all communication around potentially distressing topics would be managed sensitively. “You have ample experience of talking about difficult things with dying people so we are reassured of your sensitivity to the population.” I suggest that the assumption that my relevant clinical background automatically leads me to be an “ethical” researcher is problematic. Further, I suggest that the processes adopted by the panel did not mitigate against some of the key ethical issues that arose.

“Ellen” (discussed in Chapters 5 and 7) was admitted to Bluebell ward with a suspected brain-stem stroke, against a backdrop of end-stage heart failure and worsening kidney function. I could see that she was dying, yet over a period of five days she was intensively treated. Medically, the goal was to achieve the fine balance between encouraging her ailing heart to rid itself of the pressure of fluid building up in her lungs and the interstitial spaces in her bodily tissues, without putting so much pressure on the delicate microcirculation of her kidneys that they become unable to filter and rid the body of the excess fluid. No clinical professional had spoken to her family about her imminent death, yet I heard numerous corridor conversations in which staff shared their suspicions that she was dying. The family were keen for all treatment to continue to give her the best possible chance of survival. “Harm” was difficult to define in this case; by intervening and prompting the clinicians to recognise dying and act accordingly, I risked undermining the nursing staff. By empowering the nurses to discuss this with the medical team I risked aligning myself with one professional group and alienating myself from another. Ellen was unconscious, and the question of whether or not she was ‘suffering’ was a matter of opinion. Certainly, her family were suffering, and their imminent bereavement is likely to have been

influenced by the manner of Ellen's death, the extent to which they would have been able to say goodbye. Most importantly by intervening I would be making a clinical decision and changing the course of her dying, which clearly fell outside the scope of my responsibility. To a non-clinical external observer, the hospital was acting in expected ways - seeking to rescue the patient from the jaws of death. The risk of harms that I perceived were professionally defined. The debate around withholding and withdrawing treatment at the end of life is a complex one, and certainly by intervening here I would have been clearly positioning myself as though there is a "right" way to act in such a situation.

In the second example, "Mary" had consented to participate in the study. At this time, she was unwell and in the last weeks of life. The very act of breathing exhausted her on account of her failing heart; she woke from long periods of sleep to speak, only occasionally, in gasping and laboured single words. She told me she had been feeling "rather poorly" but that she was getting as much rest as she could to help her body get stronger. As days went on, her body ailed. Her son visited and I sat with him as the doctor explained to him that her death was near. She was in a shared bay with three other patients, one of whom was a lively woman with dementia. Staff were unable to move her to a quieter room and he was angry at her lack of privacy. He requested that I cease observations and destroy the data I had gathered up to that point. This was deeply challenging as the patient had consented for me to use the data, even if she were to subsequently lose the capacity to consent. I had spoken with her son as Consultee at the point at which she lost capacity. Given the emotionally charged nature of the conversation it was inappropriate for me to discuss in any depth the consent that she had given, nor to show him the signed consent form. I withdrew from subsequent observations and destroyed the detailed data on the few conversations and observations I had made about Mary's situation up until that point. Yet I could not shake the sense that I had betrayed her in some way, given that she had been so keen for me to include her in the study, and also that she had spent so much of her valuable last days talking to me about her life.

The fact that a project has received approval does not necessarily indicate that

the subsequent research will be ethical. RECs were originally established to safeguard the process of biomedical research, including testing of drugs and medical interventions, following the Declaration of Helsinki (WMA year). The expansion of qualitative research methods within healthcare means that these panels play a key role in approving studies that may have more flexible research questions and approaches to the data. A core tenet of many qualitative research methods is that they are inductive; that is, that they enable the study to evolve according to ongoing findings.

Concern 1: Vulnerable participants

Historically, the needs of doubly vulnerable groups of patients are ascertained through consulting proxies such as family members, or through interviewing staff such as nurses regarding the perceived barriers to care. Yet neither of these is satisfactory as both approaches are potentially biased through the self-interest of proxies. According to Moore and Miller (1999) *"some research questions can only be answered by members of a vulnerable group"* (p1034).

Yet concerns are often voiced in research about vulnerable participants feeling under pressure to participate in research. People approaching the end of life who are hospital inpatients are considered to be "doubly vulnerable by virtue of the fact that they are seriously unwell and in an unfamiliar environment. Some patients who lack capacity to consent are often thought to be at risk of harm through being involved in research. NHS Ethics Panels are particularly alert to the potential for harm for such people and there are numerous observational studies where people without capacity were intentionally excluded because of the perceived barriers to undertaking the research (Borgstrom 2014).

This is a flawed assumption on two counts. Firstly, it is underpinned by a paternalistic assumption in relation to participants' agency. Particularly where the research itself does not involve an intervention and the researcher is not otherwise involved in care provision for the patient, then even the most vulnerable of participants are able to appraise their own agenda for becoming and remaining involved in the study. Secondly, there is an assumption that the research process is burdensome in its own right, and yet there is ample

evidence as to the therapeutic nature of being afforded an opportunity to speak or to otherwise express oneself, particularly in a healthcare environment as busy as an acute hospital ward where such chances are rare. The focus on avoidance of ethical harm can obscure the wider purpose of research which is to do good.

The Declaration of Helsinki states that *"groups that are under-represented in research should be provided appropriate access to participation in research"* (Item 13), and furthermore that "research with a vulnerable group is only justified if the research is responsive to the health needs or priorities of this group and the research cannot be carried out in a non-vulnerable group" (Polit and Beck 2004). Doubly vulnerable participants are frequently excluded from research on account of perceived intractable ethical issues (Takesaka *et al.* 2004) , yet are arguably at greater risk of experiencing unrecognised suffering if unable to verbally express their needs. Research asking palliative care patients about their views on participating in research has identified that concerns that it is harmful for patients who are dying to take part in research are usually unjustified, as long as sensitive and flexible research protocols are adopted (Gysels *et al.* 2006; 2012; 2013).

Concern 2: Intrusion

The layout of this hospital ward is in bays of between four and seven beds, with two side rooms. Most patients can be seen by anyone passing through the bay, so it should be possible to undertake observation of the entire ward without any undue intrusion. Indeed, many Trusts use observation as an approach to clinical governance. However, it was also necessary to observe care ‘behind the curtain’, as this greater proximity may provide insight into the range of care given. It is imperative that the patient's dignity is upheld despite their having to undergo such interventions. A study by Billings (2009) asked older patients in hospitals what sorts of things made them feel as though their dignity and privacy were not being respected. Interestingly they did not report that the number of HCPs that they encounter during their stay impacts upon their sense of dignity or privacy, or that being observed was felt to be invasive. Sources of

distress that were identified included being patronised, left on commodes or in soiled beds for extended periods of time, treated as though they were causing disgust or aversion, or addressed in inappropriate terms.

Concern 3: Distress: cause and effect

Patients may be distressed for a number of reasons. I did not want to add to this through my presence itself being a contributory factor. If there is any indication that observation of a patient is causing distress, whether to the patient or their relatives, I will immediately withdraw completely from the observation. However, it is anticipated that the patient may exhibit signs of suffering which relate to their actual situation, rather than to the fact that their situation is being observed. I would endeavour to respond sensitively to any indication that my presence is causing distress.

One of the key concerns of the Ethics committee was in how I would manage distress arising in the course of my study. This was a topic of much discussion. I emphasised that the focus of the study is on suffering and so I anticipated that I would be highly likely to witness distress. I was keen to distinguish between distress arising from the patient's situation, and distress arising from my presence as an observer.

The committee were also keen to know that I would not ask insensitive questions or mention anything that could worsen suffering. To this end, they requested that I re-word the participant information sheets to read “non-physical needs” in place of ‘suffering’, despite my attempts to explain that these are not synonymous.

The committee seemed reassured by my professional status as a clinical nurse specialist (CNS) in palliative care, and by my additional training in advanced communication skills. I was intrigued that these were considered to be applicable to this context. I felt it was highly unlikely that I would be engaged in the types of conversations that I might have undertaken as a CNS and that becoming involved in this way might have impacted on the reliability of the

research as I stepped outside one role and into another. Nonetheless, the committee were content to grant approval on this foundation.

Concern 4: Replacing ‘suffering' with ‘non-physical needs’

The revisions that took the longest based on the feedback from the Ethics Review Panel were those relating to the wording on the Participant Information Sheets. Changes included amending the wording from ‘suffering’ to “non-physical needs” despite an attempt by me to explain why these terms are far from synonymous.

The Ethics Committee Panel involved some discussion about the use of the word ‘suffering’ in the participant information sheets. After some debate, I agreed to re-word the sheets to read “non-physical needs” in place of suffering. Although this felt like a departure from what I was seeking to research, the panel considered on balance that ‘suffering’ was too emotive and negative a word. I have written extensively in my reflexive journal about this; I was torn between wanting transparency about the topic of interest, whilst at the same time not wanting to cause upset through my choice of terminology. I decided eventually that I would concur with the Panel's wishes for the Information Sheets, but that I would be open and honest about the subject I am researching when discussing it informally with participants. This could even be an opportunity for data in itself, as I imagine these kinds of discussions will be revealing about what participants, particularly staff, think that suffering actually means.

When I was explaining the study I readily used the word ‘suffering’ with both staff and patients/relatives. I did not perceive any instance of the use of the word itself as causing suffering. I was asked several times for clarification of what was meant by “non-physical needs”, to which I responded that it was a “bit like suffering”. The latter was more readily understood.

Concern 5: Confidentiality and anonymity

Because the data was collected on a single site, protection of individual identities was essential. To protect confidentiality, alteration of some demographic details such as the age and gender of participants, and other distinguishing characteristics will be undertaken in some instances. These changes were made in such a way as not to impair the quality of the data.

Initially I planned that the site of study and the participants would be unidentifiable through the use of pseudonyms and changes of demographic data, and avoidance of lengthy verbatim quotes. Once I began collecting data I realised how difficult, in reality, preservation of anonymity would be. I had planned to return to the ward to present my findings - I wanted to involve the participants in their own data, although I realised that this would only be possible for the staff participants, as all of the patients had died or been discharged by the time I was ready to return to the ward. I knew that staff listening to the presentation would be able to identify themselves and their colleagues, as well as the patients, if I were to adopt the case study approach to presenting the findings. I therefore had to render the findings more abstract by engaging in the second wave of analysis. However, it felt disingenuous to use the full data set in the study yet present a filtered version to the participants themselves, who had given freely of their time to help with the study.

Concern 6: Informed Consent

Concerns have been expressed within anthropology about the emphasis on *informed* consent within healthcare research (Corrigan 2003). This did bring practical difficulties, particularly in relation to members of the team who were not based on the ward. In these cases, I would observe them first, explaining my role verbally, then find myself needing to scurry after them to give the information sheet and obtain a signature. This impacted on my observations, as often valuable thoughts and feelings were shared by patients after the health professional had left the room, but if I had waited they may have left the ward.

During my first few days I felt as though the stack of information sheets and consent forms I was carrying around gave me some kind of credibility as a researcher. As I collected signed forms from the never-ending stream of potential participants, I was struck by how little heed people actually paid them, despite my insistence that they do so. I felt that they constituted some kind of authority to my study, an assumption that since it had been given ethical approval and I had the appropriate paperwork, that the study in its entirety must be credible. There were very few questions relating to ethical concerns; the vast majority related to the topic itself. Nobody refused to sign a consent form.

There was an additional problem relating to the participant documentation. One of the core aims of the Research Ethics Committee is to ensure that there is transparency in relation to the study, that people can expect to know exactly what will happen to them, how often, when and where. Yet this is neither feasible nor desirable in the emergent methodology that characterises ethnographic research. Furthermore, the notion of informed consent was necessarily deceptive. I could not possibly have explained to every participant the full depth of the theory that underpinned the study, nor my own reflexive involvement, nor the phenomenological conceptual approach. At times, it was difficult to explain what I meant by ethnography and I often took recourse to simple descriptions such as *“it's how we get to know about the relationships and practices between the different people on the ward”*. These kinds of explanations felt lacking, but I was unable other than on a few isolated occasions to provide staff with any more depth. Indeed, they didn't seek it. The final information sheets that I used were therefore quite broad in their scope, and quite non-specific in their outline of what will happen. In some ways, I felt that they were so vague as to be relatively useless, a fact attested to by the number of times staff would say to me *“what is it you're researching, again?”* even when they had already signed a consent form.

Although the information sheets had been developed in collaboration with a group of Experts by Experience, and the Research Ethics Committee had requested four amendments to the wording, I was left with a sense in which the participants were at best only partially informed about the study. In part, this

relates to the nature of ethnographic research itself, whereby the nature of the observations and the objects and aims of the study are continually evolving in response to the experiences in the field.

In preparation for inclusion of participants who lack capacity, a process was outlined for identifying consultees who would be approached and asked to consent if they perceived that this was in accordance with what the person might have accepted, should they have had capacity. In practice, this was much more complex than anticipated. Several patients did not have visitors and it became necessary for members of the healthcare team who were not directly involved in that person's care to become consultees on their behalf. The REC committee had stipulated that consultees must not be involved in any way with the research, including as participants. However, those members of staff not involved in the person's care were inevitably less likely to know the patient, and therefore their agreement to consent felt less informed than had I been able to approach a member of staff currently who was currently actively involved. I circumnavigated this obstacle by consulting staff nurses who had cared for the patients on previous shifts but who were not allocated to that ‘pod’ on the day when I was to undertake observation.

Some patients had capacity when I initially approached them but then lost this as they became more unwell, or because they were asleep or unconscious when I visited subsequently. In these cases, I based my decision about whether to continue to observe them on my previous relationship with them. Often, I asked patients as I left if they would be happy for me to return, sometimes asking whether there were any situations that they would not want me to observe. This felt as though I was avoiding straight talking but I was concerned that if I asked outright about observing them if they were more unwell this might provoke anxiety.

In one instance, I obtained consent from a patient who had been admitted with worsening heart failure. I had also had an opportunity to discuss the project with her son and best friend, both of whom agreed with her decision to consent. It became clear that her condition was worsening and she lost consciousness.

Her son approached me and requested that I discontinue my observations ‘given the circumstances’. I did so, although I was aware that I was doing this to lessen his distress and not because she would have necessarily been likely to withdraw her consent. However, given the sensitive nature of the situation I did not pursue this further. Nevertheless, I did obtain his consent to use the notes that I had acquired up to that point.

Appendix 3 – Staff Participants

Pseudonym	***Profession***	***Demographic info***
Nursing Staff and Support Staff		
Brett	Nurse, qualified 4 years - has always worked with older people.	Originally from Caribbean, trained in UK and has worked in various clinical settings. Older people's care is his favourite.
Rebecca	Staff nurse	Qualified for 6 years, worked in this setting for last 2
Jasmine	Healthcare assistant;	Wants to do her nursing training. Enjoys end of life care.
Alvar	Qualified nurse	Recently arrived from Portugal on working visa.
Rachel	Qualified nurse	Recently qualified, currently undertaking her 'Supporting Learning in Practice' module to allow her to mentor student nurses
Edith	Dietary assistant.	Used to be a healthcare assistant, new role was created to support patients at mealtimes. If patients are not able, Edith is responsible for ordering meals, coordinating assistance with eating
Liz	Matron.	Has responsibility for several wards across two hospital sites.
Sue	Ward sister	Worked here for 11 years, feels like the Francis Report has changed things for the worse. Hopes to be able to take early retirement
Hannah	Newly qualified staff nurse	Wants to work in acute care but hasn't made mind up yet, thinks older

		peoples care is a good foundation as it gives you a *"bit of everything"*
Kirsty	Staff nurse	Qualified for three years and has worked on same ward since qualifying
Pam	Staff nurse, qualified for 36 years.	Has always lived in this area but has seen changes in the local community. Thinks people's health is getting worse, not better
Mercy	Agency nurse,	Originally from Namibia but has lived in UK for ten years. Devout Christian.
Claire	First year student nurse,	Lives locally with parents, wants to work in A&E when qualified
Sonia	Healthcare assistant, 48,	Originally from Pakistan but she moved to UK to marry twenty years ago. Thinks old people should be cared for at home and that it is sad when they are in hospital
Becky	Staff nurse, 32, qualified 6 years.	Used to be a policewoman. Grew up in local area
Keely	Healthcare assistant,	Grew up in local area. Used to work on gastroenterology but found it too stressful
Cheryl	Qualified nurse	Mostly works right shifts because it fits in with her 'other job' as a grandmother. Keen to retire.
Eve	Healthcare assistant	Wants to do her nurse training one day
Sue	Discharge coordinator	New band 4 post. Previously had worked as Healthcare Assistant on the ward for 6 years
Wendy	Specialist palliative care nurse	Works across the hospital and takes referrals from all wards. Has

		worked as a Macmillan Nurse for 4 years, prior to that in Oncology and Hospice nursing. Trained as a nurse in a large city, moved to this area 10 years ago.
Dot	Staff nurse	Describes herself as *"also a poet and artist".*
Jane	Clinical Site Commander	Works across the hospital to coordinate admissions and discharges, known as 'patient flow'. Does not communicate directly with the ward - instead does so via the 'Discharge Coordinator' (DC) - each ward has its own DC, usually a healthcare support worker who has had additional training to fulfil the new role.
Jean	Domestic Assistant	Has worked on this and similar wards for over thirty years.
Helen	Ward administrator	First point of contact for visitors to the ward. Also, administrative responsibilities such as making up patient notes, filing and triaging calls.
Medical Staff		
Dr Roberts	Consultant in Older Person's Medicine	Has worked in the hospital for over 15 years
Dr Frank	Junior Registrar	Currently on rotation in Older Person's Medicine but wants to specialise in Gastroenterology Originally from Nigeria but never practised medicine there, but would like to go back one day
Dr Burton	Junior Registrar	Grew up near London but undertaking medical training in the North of the UK

Dr Rockwood	Senior Registrar	British, from London, travelled to North to be with partner but doesn't feel she *"quite fits"*
Dr Ben	FY1 (newly qualified doctor)	His parents are from China but he was born in UK. Qualified in nearby medical school, not sure what speciality he wants to enter.
Dr Keira	FY1 (newly qualified doctor)	From Malta, has lived in UK since arriving to do medical training
Dr Basu	Consultant in Older Person's Medicine	Originally from the Bengal area of India, has lived in UK for 22 years. He has worked in this hospital for 4 years.
Dr Fischer	Consultant in Older Person's Medicine	She has worked in the hospital for twelve years. Originally from Germany but trained in the UK. Involved in clinical education and link worker for palliative care within the hospital.
Allied Health Professionals		
David	Rehabilitation assistant:	Supports physiotherapist (Sophie) by implementing and evaluating plan of care
Sally	Dietician	Works closely with Dan (below). Assesses patients thought to be at risk of malnutrition
Dan	Speech and Language Therapist	Assesses patients thought to be unable to swallow safely, advises on changes to diet
Jo	Social Worker	Accepts referral from patients once 'medically stable' and assesses needs after discharge, also sees patients where there are concerns

		about safeguarding or other social issues
Kerry	Occupational Therapist	Accepts referrals for patients when home is planned to assess function and activities of living
Kate	Physiotherapist	As above in relation to mobilising, transferring; key role in safety. Works across hospital and usually gets to Bluebell Ward by late morning as has to see ‘front end’ ward patients first to sustain patient flow (e.g. medical assessment ward)
Alice	Lead Clinical Site Commander	Oversees ‘patient flow’ across the hospital site

Appendix 4 – Patient Participants

Patient participants are listed here in the order in which they appear in the thesis

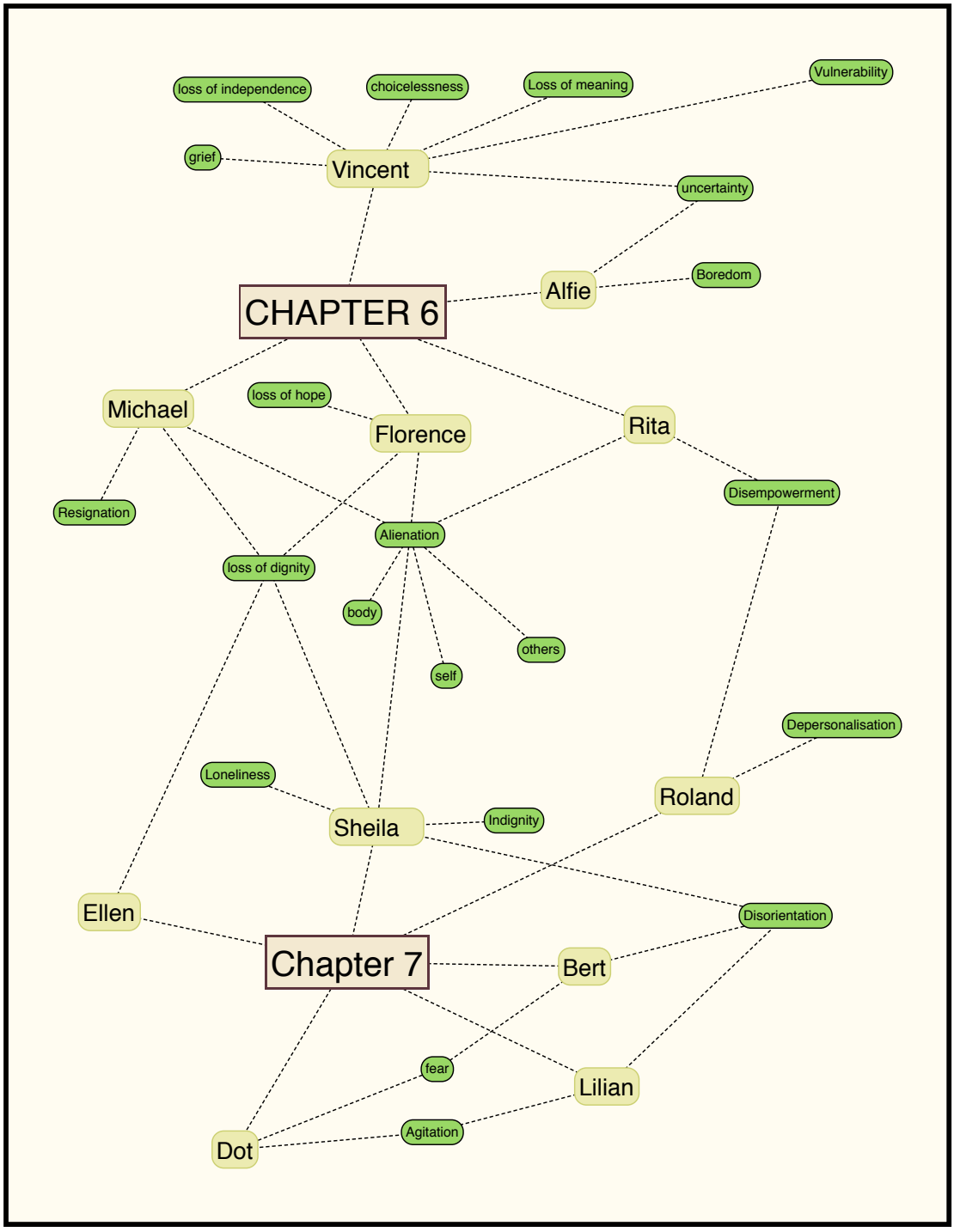
Pseudonym	***Demographic and clinical information***
Vincent	84 years old with end-stage chronic obstructive pulmonary disease, admitted to ward with infective exacerbation. Inpatient for 22 days, admission ended in death.
Dot	88 years old with dementia and cancer, admitted with worsening confusion. Recently diagnosed with cancer and decided not for active treatment. Admitted for 11 days, discharged on 'Fast Track' package to die at home
Sheila	77 years old with dementia, also had a pressure sore infected with MRSA, was admitted with worsening confusion from a residential home. Had been in the hospital for over four weeks prior to the fieldwork and was still an inpatient at the end. Became gradually bedbound. Discharged to a nursing home where she died two months later.
Doris	72 years old, admitted for investigations of syncope (fainting). Cardiac problems diagnosed, plan is for home with referral to Heart Failure nurses.
Florence	65 years old, admitted with persistent diarrhoea and dehydration, also has bilateral leg ulcers infected with MRSA. Diarrhoea diagnosed as *E.Coli*. Nursed in a side room. Issues with pain in legs. Eventually discharged to care home after 6-week admission.
David	81 years old, admitted having fallen down the stairs at home and sustained multiple fractures. During admission became acutely unwell with a urinary tract infection from which he recovered. He was still an inpatient at the end of the field work as no suitable placement could be found in the community.
Ned	90-year-old man with dementia, admitted with a severe chest infection. Initially thought to be dying but

	responded to antibiotics. However, concerns persisted about risk of aspiration. Debates regarding ethics of feeding tube but he and family declined. Admission for 18 days.
Edward	79 years old man with dementia, admitted with pneumonia which was treated with antibiotics but he did not respond, and his condition continued to deteriorate. He died 9 days after admission.
Rita	94 years old with end-stage heart failure, admitted with worsening symptoms of shortness of breath. Improved with treatment with diuretics.
Paul	88-year-old man with advanced dementia and a chest infection that has not improved despite antibiotics, steroids and oxygen. He deteriorates rapidly and dies 4 days after admission.
Alfie	69-year-old man admitted after taking an overdose but subsequent investigations suggested no overdose had been taken, however he had multiple symptoms that were investigated without a clear diagnosis. These did not improve over the course of his 8-day admission. He self-discharged home against medical advice.
Michael	72 years old, admitted from warden-controlled accommodation with a grade 4 pressure ulcer that was infected. Dependent on carers for everything. Investigated for possible sinus formation. Treated with antibiotics. Did not improve during admission. Discharged to nursing home 23 days after admission.
Ellen	68 years old with end stage heart failure and renal failure, admitted from home with a suspected stroke or seizure. Investigations inconclusive. Deteriorated during admission and died 9 days after admission
Bert	94 years old, admitted with chest pain and dizziness. Developed delirium whilst an inpatient. Discharged to care home 18 days after admission.
Lilian	85 years old, admitted via A&E from nursing home with delirium against a background of dementia. Develops numerous problems during admission – still an inpatient when fieldwork finished but had

	deteriorated significantly. Questions over whether could go back to same nursing home
Roland	84-year-old man admitted from a care home for investigation of falls. Admission lasted 16 days, no conclusive diagnosis identified.

Appendix 5 – Patient Participants mapped to themes of suffering

Figure 17: Themes of suffering



Appendix 6 – Sample Observational Chart

(adapted from Roller and Lavrakas 2015)

Area of observation	Outside sluice in corridor
Who?	1 staff nurse, 1 agency nurse and a student physio
Behaviour / demeanour	Casual, laughing
Conversation	Nurses are talking about how some of the physiotherapists come and get them if a patient needs the loo while they are reviewing them
Verbatim comments	*"too posh to wipe up crap"*
Context	The student physio is new on the ward
Person characteristics	Comfortable and at ease with one another, all in uniform. Staff nurse seems "in charge" – wearing lots of coloured badges on her uniform and a rainbow clip in her hair. Smiling but formidable.
General mood	Relaxed
Other areas of observation	The corridor is busy – it's lunchtime and the trolley is being trundled on to the ward
Sensory notes (smells, sights, sounds etc.)	Behind them the sluice machine is making noise and the sounds and smells of lunchtime are happening. There are several beeps – patients needing the toilet. The other nurses are busy.
Reflexive notes	Are the nurses making sure the student physio knows "the rules" (in their book)?

Appendix 7 – Research Outputs

Conference Presentations

Middleton-Green, L (2015) **Breaking down the walls**, Royal College of Nursing Research Conference, London

Middleton-Green, L (2015) **Suffering in peripheral vision,** Ethnography and Health, London School of Tropical and Hygiene Medicine

Middleton-Green, L (2015) **"Making a drama out of a question mark": findings from an ethnography**. Allied Health Professionals End-of-Life Care Conference, Leeds Teaching Hospitals NHS Trust

Capstick, A and Middleton-Green, L (2016) **Breaking Repression**, Everyday Ethics, Royal College of Nursing, London

Middleton-Green, L (2015) **Connecting the World: Twitter in end-of-life care practice, education and research,** Marie Curie / Royal Society of Medicine Research Conference, RSM, London

Middleton-Green, L and Russell, S (2015) **Relational Conversations**, Hospice UK Conference, Liverpool

Middleton-Green, L (2016) **Adapting sensory ethnography to research patient experience**, Palliative Care Congress, Liverpool

Middleton-Green, L (2016) **"Will you tell me how I am?" End of Life Care in Dementia,** Yorkshire & Humber Acute Dementia Champions, Wakefield

Posters

Middleton-Green, L (2016) "**But I'm Not a Doctor": choice and non-choice in conversations about cardiopulmonary resuscitation,** Palliative Care Congress, Harrogate

Blog

Reflections on Compassion in End of Life Care

https://lmiddletongreen.wordpress.com/

Books

Middleton-Green *et al* (2016) **End of Life Care in Dementia**, London: Jessica Kingsley Publishing

Green, L and Spencer, S (2017) **Change Management in Palliative Care**, in press